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Aotearoa New Zealand emergency ambulance services and the provision of end-of-life care: a short survey

Andrew Munro, Kate Grundy, Sara Davis

As total annual deaths are set to rise by 50% in the next two decades, front-line ambulance crew can expect an increase in the number of clinical encounters in and around the provision of end of life (EOL). This large survey asks ambulance crew specific questions about EOL care. There was a perceived need for more education and training in helping with quality decisions around EOL care. A minority of the ambulance workforce feel they are culturally competent when it came to the provision of EOL care to iwi. Mental health of frontline staff may benefit from organisational pastoral care.

PATHA's vision for transgender healthcare under the current health reforms

Jaimie F Veale, Jemima J Bullock, Jack Byrne, Moira Clunie, Tommy Hamilton, Jove Horton, Zoe Kristensen, Joey L Macdonald, Jeannie Oliphant, Dionysius Reid, David Sar Shalom Abidi, Catherine J Stephenson, Cassie Withey-Rila, Penni Wolfgramm, Rita Yun-Tai Yang, Rona Carroll

The healthcare system in New Zealand does not adequately meet the needs of transgender people, but the Ministry of Health has met with the Professional Association for Transgender Health Aotearoa (PATHA) to find ways to improve the system. PATHA proposes improvements to transgender healthcare, including the creation of a new transgender health resourcing hub that operates under a Te Tiriti o Waitangi framework, provides national coordination of a distributed model of care and actively works to resource primary care and gender-affirming surgeries. The proposed changes aim to make healthcare for transgender people more equitable, accessible and cohesive by utilising peer health navigators, education and professional development, healing-focussed care and transgender community leadership and accountability to make healthcare more equitable, accessible and cohesive for transgender people. The aim is to take the best practices from existing regional programs and implement them throughout the entire country.

Genetic discrimination by insurance companies in Aotearoa New Zealand: experiences and views of health professionals

Harry Fraser, Kimberley Gamet, Sally Jackson, Andrew Neil Shelling, Paul Lacaze, Jane Tiller

In Aotearoa New Zealand, both life and health insurers can use genetic results legally to discriminate against applicants. Our study of New Zealand health professionals found that New Zealanders are experiencing discrimination in insurance, and that fears of this discrimination are deterring people from having potentially life-saving genetic tests. Health professionals are very concerned about the impact this is having on patients, and overwhelmingly believe government legislation is required to regulate this area.

A review of trauma laparotomy at Christchurch Hospital

Tengo Kandelaki, Melissa Evans, Christopher J Wakeman, Andrew McCombie

Multiple factors contribute to decide that an operation is required for abdominal trauma. Identifying injuries on scans is a contributing factor in the decision-making process. Potentially missed injuries on the trauma scan could delay management of injuries and result in worse outcomes. Our study found no difference in mortality in patients who had injuries missed on scanning compared to patients with no missed injuries prior to their operation.

Food security during nuclear winter: a preliminary agricultural sector analysis for Aotearoa New Zealand

Nick Wilson, Marnie Prickett, Matt Boyd

This study considered potential food security for Aotearoa New Zealand during "nuclear winter" scenarios following a nuclear war in the Northern Hemisphere. It used published data, including those from the impacts on food production in New Zealand during three nuclear winter scenarios. It found that this country could theoretically have excess food production capacity, even after a severe nuclear winter scenario. But this benefit could be very short term if the agricultural system was not made more resilient to potential lack of international trade and socio-economic collapse in a post-catastrophe setting.

Constraints on medication-based inflammatory bowel disease therapy in Aotearoa New Zealand—why medication adherence is important

Obreniokibo I Amiesimaka, Rhiannon Braund, Kristina Aluzaite, Michael Schultz

With cases set to double within the decade, and considering its substantial costs to New Zealand, Inflammatory Bowel Disease (IBD) constitutes a material burden to patients and society. Medication adherence is important for IBD management to secure the health and wellbeing of patients; however, adherence levels are often sub-optimal, which can lead to disease escalation alongside increased morbidity and mortality, disability and health costs. Despite the funding of two new biologic medications for therapy in New Zealand, further expansion of the therapeutic landscape by funding more medications, already available abroad, and allowing for flexibility in the use of top-level medicines, would be beneficial to patients. However, given the current situation, medication adherence is especially important for New Zealand patients with IBD to maximally benefit from available medications. Thus, medication adherence research and interventions should be prioritised to aid IBD, and other chronic disease, management.

Optimal trauma care delivers cost savings: the New Zealand Trauma Network experience

Ian Civil, Siobhan Isles

It is often quipped that a project can be fast, high quality and low cost, but not all three. In the case of the National Trauma Network (NTN), it has delivered improved patient outcomes in a relatively short time frame and crucially has demonstrated objective cost saving to the health system.

The triple aim embodied in quality improvement literature aims to produce better outcomes for the patient, for the population and for the system.[1] The nature of healthcare delivery in New Zealand means that it is often difficult to quantitate the financial benefits to the system for any quality improvement initiative. Trauma is an exception in that it is not only provided by the Accident Compensation Corporation (ACC) on a bulk-funded basis for pre-hospital and acute care but also on a fee-for-service basis for rehabilitation. In addition, the costs of lives lost are also borne by ACC, with its responsibility not only for immediate funeral costs but also for long-term support for dependent children.

The NTN was formed by the then Minister of Health in 2012 on the advice of the Quality Improvement Committee. Initially under the governance of the Ministry of Health, this role shifted across to ACC in 2015 when it was recognised that this organisation had the most to gain financially from better trauma care. Reduction in mortality rates and improved recovery of survivors would produce quantifiable financial gains for ACC. As a result, a series of business cases and subsequent contracts with the Trauma Network leadership have included specific Key Performance Indicators (KPIs) relating to financial targets and allowed the Network leadership the relative autonomy necessary to achieve these. The most recent business case covered the period July 2018 to June 2023.

The NTN was set KPIs in relation to case fatality rates, return on investment, average cost per claim and return to independence as well as a range of other patient-focussed KPIs.

Case fatality rates have continued to fall, and in the time period from 2018–2021 fell from 9% to 7.4%, which equates to approximately 35 lives saved each year.[2] A similar drop is also observed for Māori who experience major trauma. Individual claim costs have fallen by 4% leading to cumulative direct cost savings to ACC of $7.15 million. The cost benefit analysis of the trauma programme to ACC is for every dollar that is spent, two dollars are saved. As the benefit is cumulative, further savings are projected.

While the direct value of lives saved is modest, the recent valuation of the monetised benefits and costs published by Waka Kotahi was $4.1 million per death,[3] which would put the benefits of the 105 lives saved over this period as $430.5 million.

Disability-Adjusted Life Years is a metric widely used for measuring health loss. In a recently published study, the cost of health loss of hospitalised major trauma patients in New Zealand was estimated at $1.02 billion, and reduced per case by $19,170 over 3 years.[4] This saving applies to ACC and health agencies, and most importantly to individuals and New Zealand society as a direct result of improved trauma care.

These achievements have been delivered in the context of immense disruption to the programme of work. Aside from the recent impact of COVID-19, the governance structure of the NTN has been changed numerous times by the Ministry of Health and ACC and, presently, Te Whatu Ora – Health New Zealand.

Despite these challenges, the trauma programme has succeeded for many reasons. The committed teams in hospitals and regions have been and continue to be the backbone of delivering quality trauma care. The Health Quality & Safety Commission has planned and delivered effective trauma quality improvement programmes and the relative autonomy of the Network has allowed trauma leadership at national and regional levels to be nimble and focussed.

While it is not possible to monetise the savings delivered by other health networks it is likely that effective systems all generate improvements of

care and save money. Variations in healthcare delivery is one of the factors associated with poorer outcomes—and efficient national systems reduce this. Te Whatu Ora – Health New Zealand offers the opportunity to deliver equitable care regardless of where the person was injured or any population characteristic. Using a financial model and KPIs has also allowed the NTN to quantitate expected and actual savings, justifying funding being specifically allocated to meet these expectations. This model of healthcare provision is not presently possible for other forms of publicly funded healthcare, but in the case of trauma allows clear demonstration of its benefits and justifies further investment.

New Zealand has an established contemporary trauma system and is now regarded as being among the best performers internationally. Not only do more people survive today than they did previously, but those who survive have lower levels of disability and this is reflected in the cost of delivering care. To continue to achieve the improvements in trauma care outcomes on the triple aim will require preservation of the key elements of the NTN that have been built up steadily over the last decade. The present health reorganisation is both a challenge and an opportunity—and hopefully both the effective structure of the NTN will be preserved and many new networks established that can use the evidence of patient, societal and financial benefits apparent from the NTN experience to shape their development.

COMPETING INTERESTS
Nil.

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How does the HDC Code apply in the context of delays?

Morag McDowell

There is no doubt the health and disability sector is currently under significant pressure. This pressure, together with issues introduced by the COVID-19 pandemic, has been reflected in an unprecedented increase in complaints to the Health and Disability Commissioner (HDC). HDC received a 25% increase in complaints in the 2021/2022 financial year, and complaint volumes continue to be high in the current year to date.

A number of these complaints reflect concerns by people about delays in care, constrained access to services and inadequate communication with them in the context of these delays. Complaints highlight the impact that delays in care can have on people, both physically and psychologically, particularly where their health is deteriorating and there is a lack of certainty about when care will be received.

Application of the Code in the context of delays

My role as the Health and Disability Commissioner is to promote and protect the rights of people using health and disability services as set out in the Code of Health and Disability Services Consumers' Rights (the Code). The Code gives people a number of rights, including the rights to: care of an appropriate standard that meets their needs and upholds their dignity and mana; freedom from discrimination; effective communication; the information they need to make an informed decision and give their informed consent; and to complain about the services they receive. The Code places corresponding duties and obligations on providers and is enforceable by law.

The Code states that a provider is not in breach of the Code if the provider took reasonable actions in the circumstances to give effect to the rights and comply with the duties in the Code, and circumstances in this context includes the consumer's clinical circumstances and the provider's resource constraints. The onus is on the provider to prove that it took reasonable actions. When assessing complaints, HDC invariably takes into consideration the relevant broader circumstances and context within which the care occurred.

An appropriate standard of care

The Code does not give people the right to access services, and HDC cannot compel care to be provided to someone. However, providers do owe people waiting for services a duty of care, including the right to care of an appropriate standard (Right 4) that minimises potential harm to them and optimises their quality of life (Right 4[4]). This includes minimising delays and providing care within acceptable timeframes where possible, particularly for care that is time dependent. It is also expected that providers are appropriately assessing and prioritising people on a waitlist to ensure those with greater acuity and need are seen first; that is, that prioritisation systems are fair and effective.

I outline some cases below where HDC has found providers in breach of Right 4 of the Code (an appropriate standard of care) in respect of care delays.

I recently found Te Whatu Ora – Southern (formerly Southern District Health Board [DHB]) in breach of Right 4(4) of the Code for delays in the provision of non-surgical cancer services between 2016 and 2022.[1] Due to poor clinical governance systems, including inadequacies in quality measures and indicators, and poor relationships between clinicians and executive leadership, Te Whatu Ora – Southern failed to recognise and adequately respond to the clinical risk associated with lack of capacity and consequent delays within its non-surgical cancer service. As a result, people with cancer were harmed. In respect of this case, I commented:

> *"Providers owe a duty of care to people waiting for resource constrained specialist procedures, particularly when the intervention is time critical… an effective accountability and performance framework where patients are the focus and patient safety concerns are signalled, acted upon and evaluated is*

> *a vital component of quality and risk management… This case is a salutary reminder of the detrimental physical and psychological outcomes for patients when the system does not adequately provide for timely cancer care."*

I also found a district in breach of Right 4(1) of the Code for a failing to provide care with reasonable care and skill in relation to not ensuring that radiology reporting was completed in an acceptable timeframe.[2] In this case there was a delay of 11 days before a chest X-ray image, which showed a mass-like lesion, was reviewed and reported on by a radiologist. In respect of this case I noted:

> *"I am, of course, aware of the pressure radiology services are under at a national level due to increase in demand paired with workforce shortages and recruitment challenges. Fundamentally, however, it is my view that healthcare consumers have the right to expect X-rays to be read in fewer days than occurred in this case. That such delays are common does not excuse the delays, and I am concerned that if a culture of tolerance of unacceptable delays develops across DHBs, this will become normalised and patients will be put at risk. The passage of time between seeing a patient and reviewing a radiology report does not support good clinical decision making, and the timely reporting of radiology results is a critical systems issue."*

Deputy Health and Disability Commissioner, Dr Vanessa Caldwell, found a DHB in breach of Right 4(1) of the Code for delays in care provided to a six-year-old boy with symptoms of reduced vision by the ophthalmology service.[3] Due to long delays in care, the boy's family sought care privately where he was diagnosed with a brain tumour. In particular, the Deputy Commissioner was concerned that both his referrals were graded incorrectly by an orthoptist without the direct supervision of an ophthalmologist and in the absence of appropriate guidelines, and that the DHB failed to meet Ministry of Health timeframes for first specialist appointments (FSA). While the Deputy Commissioner acknowledged the pressure on ophthalmology services and associated workforce shortages, she noted that provider accountability to address these issues is not removed by systemic pressures. She also raised concerns that this was not the first time HDC had investigated delays in this ophthalmology service. The Deputy Commissioner commented in respect of this case:

> *"I am very critical of the length of time it took for Master A to be seen at the DHB for an FSA, noting that Master A's symptoms could well have been indicative of a health issue that was time sensitive… It is concerning that in order to receive treatment within a reasonable timeframe, Master A's family had to seek care privately."*

Communication with consumers about delays

Right 6(1)(c) of the Code gives people the right to information that a reasonable consumer—in that consumer's circumstances—would expect to receive, including information regarding the estimated time within which services will be provided.

In the current environment, where pressure on the system can often result in delays, proactive, transparent communication is important for managing patient expectations. Waiting for care can be an anxious time for patients and their whānau, and complaints often reflect their frustration with a lack of information about reasons for delays and time-frame expectations. It is important that consumers are provided with information about reasons for delays, any alternative options for care and estimated timeframes. Clear safety netting advice is also important in this context, with patients needing accessible information about when to contact their health professional while waiting for care.

For example, in regards to cancer care delays at Southern DHB, I was critical of the level of communication and support provided to people on the waitlist. In that case, patients and their whānau would have benefited from a more consumer-centric approach to communication that included a single point of contact within the district to ensure they were well informed, supported and knew what to do if their circumstances changed.

Conclusion

The Code is the benchmark for consumer-centred care in Aotearoa New Zealand. I am very cognisant of the current pressures on the health and disability system and its workforce, and have been

impressed by the dedication providers continue to show to providing high-quality, consumer-centred care in spite of these pressures. Notwithstanding such pressures, the Code remains of central importance in this context, and it is critical that we continue to guard against complacency or tolerance in regards to delay and the potential for patient harm. While I understand that the constraints on the system are complex and will take time to address, all people have the right to services that minimises the potential harm to them and optimises their quality of life.

COMPETING INTERESTS
Nil.

AUTHOR INFORMATION
Morag McDowell: Health and Disability Commissioner
Morag McDowell began her term in September 2020. She is committed to promoting and protecting the rights of health and disability services consumers where the Code sets the benchmark for good practice, and opportunities for learning and quality improvement are embraced. She strongly values the importance of fair, timely, transparent, and culturally appropriate processes where people are engaged, and given the opportunity to be heard. Morag took up the role after serving nearly 13 years as a Coroner based in Auckland. She was formerly a Crown Prosecutor, Director of Proceedings for the Health and Disability Commissioner's Office, and a Senior Legal Adviser at Crown Law. Since completing her Master of Laws degree, her legal practice has had a strong focus on healthcare law, and she has appeared in different courts and tribunals on a variety of health-related litigation. She has also lectured and published on a range of medico-legal issues.

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Aotearoa New Zealand emergency ambulance services and the provision of end-of-life care: a short survey

Andrew Munro, Kate Grundy, Sara Davis

ABSTRACT

AIM: To characterise emergency ambulance service (EAS) clinical roles and experiences (including cultural competency and pastoral care) in the delivery of end-of-life (EOL) and palliative care in Aotearoa New Zealand.

METHOD: A nine question online survey was distributed to St John and Wellington Free Ambulance clinicians. Four questions enabled voluntary free-text comments to be submitted for thematic analysis. A further opportunity for free-text comments was available at the end of the survey.

RESULTS: There were 444 participants, which is 14% of the paid ambulance workforce. 63% reported that they frequently transported EOL care patients to hospital when they could be better managed at home. EAS clinicians depend heavily on informal collegial support for pastoral care as formal debriefs are rarely offered.

There were 671 free-text comments. Dominant themes included the importance of seniority, the need for further education, the importance of documented care plans and the need for better integration with community services, including hospice.

CONCLUSIONS: More can and should be done to ensure EAS clinicians are supported to deliver quality EOL care for patients alongside other community providers.

As the population of Aotearoa New Zealand ages over the next 20 years, total annual deaths are expected to increase by 40–50%.[1] About 70–80% of people aged 70 years and over have at least one emergency department (ED) encounter during the last 6 months of their life and hospitals remain the single most common place of death for this group.[2] Trends towards fewer unexpected or sudden deaths and a consistent preference by the public for death to occur at home present a major opportunity for planned end-of-life (EOL) care. Input from specialist palliative care is not necessary for all patients, so it is incumbent on every clinician to recognise the role they can play in providing quality EOL care that is in line with patient preferences. Early palliative care reduces the need for emergency care as well as hospital admissions.[3,4] This is often referred to as "shared goals of care" and should be a prime objective when providing care and treatment at the EOL.[5,6]

A recent survey of Aotearoa New Zealand ED specialists found that there was a high level of engagement around EOL care. However, there is minimal training and experience in palliative care principles, serious illness conversations and cultural competency. Pastoral care for ED clinical staff around death and dying is haphazard.[7]

Emergency ambulance services (EAS) provide 24-hour availability for assessment and treatment in community settings. The scope of practice for EAS has broadened over recent years and with sufficient training and support ambulance personnel can practise non-resuscitative/supportive EOL care at home.[8,9] The extent of both training and expertise across the EAS, however, is variable and depends on the specific role and context. Extended care paramedics (ECPs) receive specific training in the principles of palliative and EOL care, however, they are not available in all regions.[10,11]

The aim of the survey was to characterise and explore the current understanding/role that ambulance personnel have about the provision of care for palliative patients who are at or near the end of life.

Method

The study was registered with the New Zealand Health and Disability Ethics Committee (HDC): project number 11730. HDC considers the study to be out of scope for formal ethics approval. Ambulance service Hato Hone Māori local committee approval for this work was obtained in

November 2021.

A link to the survey was distributed to St John and Wellington Free Ambulance services. The survey opened on 21 January 2022 and closed on 24 July 2022. There were nine questions in total, with the first two covering the respondents' ethnicity and authority to practice and the last two enquiring about length and location of practice.

Remaining questions asked EAS personnel about their experiences and opinions around pre-hospital provision of EOL care, access to patient wishes and preferences for care and treatment, self-assessed cultural competency regarding EOL care for Māori and their whānau and information about the provision of pastoral care within the EAS. Statements and questions around the provision of EOL care required Likert -scale responses from five categories: strongly agree, agree, neutral, disagree, or strongly disagree. For analysis purposes, results are shown as three levels: agree, disagree or neutral.

None of the questions were compulsory. Each question included a space for free-text comments and comments were also invited at the end of the survey.

Statistical analysis

Participant responses are reported as counts and proportions are shown as percentages.

Using the methods described by Braun and Clarke,[12] free-text comments were systematically analysed for common themes.

Results

A total of 444 of 3,200 (14%) of the paid EAS workforce participated. The majority self-reported as European/ Pākehā with only 32/444 (7%) identifying as Māori.

Most of the respondents were paramedics or emergency medical technicians (EMTs). There was a high response rate from ECPs given that the total number across the country is less than 50. Figure 1 shows the total count for authority of practice for EAS participants.

Urban centres accounted for 203/444 (46%) of participants, 127 (29%) were rurally based and 107 (24%) were regional.

There were 50 of 443 (11%) of EAS crew who had worked for 3 years or less, 159 (34%) with 3 to 10 years and 244 (55%) with more than 10 years of work experience respectively.

Survey question 3

Four statements around the provision of EOL care were asked. Table 1 shows proportional results with totals of participants for each statement.

This section of the survey produced 112 free-text comments. Five interrelated topics of discussion were dominant. In descending order of frequency these are listed below.

- The need for more community services
- Seniority, education, training, guidelines, and pathways
- Advance care planning (ACP)/shared goals of care
- Remote clinical advice
- Non-core activity

Community services

The need for more community services (including hospice and palliative care) were expressed in 67 of the 112 (60%) available comments. Closely linked was the notion that planned care better prepared patients and their whānau and established clearer indications for care in the home and for transport to hospital.

Also highlighted were the need for better support for aged residential care (ARC) facilities and the strengthening of ties and sharing of data between services (primary care, ARC, ambulance, palliative care and hospice services).

The need for training education, guidelines and pathways was linked to the theme of community services in almost half the comments.

Enabling people to remain at home was an important sub-theme and transporting to hospital was often seen as a systemic failure.

> *Community palliative care teams invariably perform better in this role than ambulance staff do. Improvements to community based palliative care services would be of more benefit than upskilling ambulance staff.*

> *…being dragged out of their bed and home to go to ED for "comfort cares" is not necessarily in the best interest of the patient.*

> *Transport to ED often the easy option. Taking time to seek better solutions is overlooked.*

Figure 1: Ambulance personnel authority of practice.

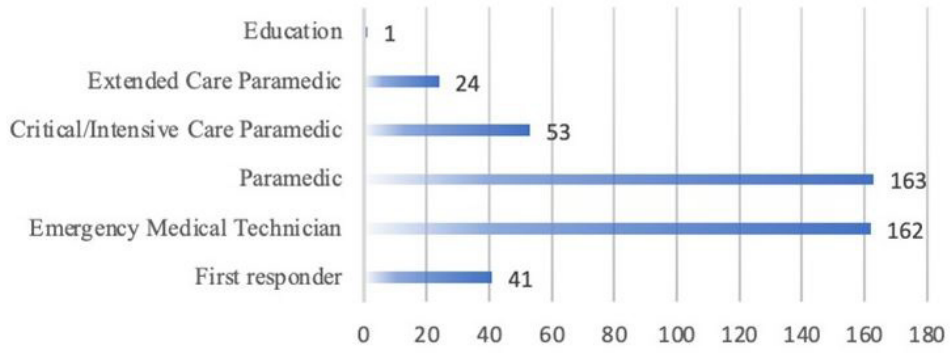

Table 1: Simplified Likert scale responses to survey statements.

Statement	Agree (%)	Disagree (%)	Neutral (%)	Total
Ambulance services can almost always provide appropriate EOL care without transport to hospital.	50	47	3	433
Ambulance services frequently transport patients to hospital who could be better managed at home.	63	18	19	435
There should be more training of crew in serious illnesses and goals of care conversations.	93	6	1	433
If it were available, after-hours remote medical advice would be used more often.	88	11	1	437

Table 2: Pastoral care for ambulance crew.

Following the death of a terminally unwell patient...	Always/often (%)	Sometimes (%)	Rarely/never (%)	Total
You feel well supported.	44	28	28	416
Formal debriefs are offered.	17	21	62	424
Psychological support is available.	59	25	16	425
Informal collegial support is available.	77	19	4	428

I have transported end-of-life patients under palliative care for no other reason than the inability of caregivers to manage the end-of-life process, this includes some aged care home residents unfortunately. Our local hospice is not usually able to send anyone out to assist.

These types of jobs cause me significant anxiety and stress as I feel I have no tools or resources to actually help improve or offer comfort for the patient and more often than not disappoint the family from the level of care we can provide.

…an absence of effective communication and/or guidelines between Paramedics and Hospice results in inappropriate transport to hospital.

Wrap-around services with clear patient-centred goals that family members can understand need national attention.

Seniority, education, training, guidelines and pathways

There were 50/112 (45%) comments expressing a desire for more training and/or for the provision of better pathways and guidelines. The role of senior training and experience (or lack of) was recognised in 14/50 (28%) of these selected comments, 12 of which were linked to training and education. Underpinning this, 87/203 (43%) first responders and EMTs vs 133/241 (55%) paramedics and above agreed that ambulance personnel can almost always provide EOL care without requiring transport to hospital and 20 of 24 (83%) ECPs felt that patients were frequently transported to hospital when care at home could be more beneficial.

Experience and qualification of the attending officers can influence how end-of-life care patient is managed.

Training in EOL care for paramedics is minimal.

I have moved from a major metropolitan area to a semi-rural region. In the main centre, exposure and training was more detailed. In this region, training is ad hoc *and not recorded.*

If Hospice has supplied the medications, there is a gap in understanding the effects, administration and discussion around medications due to EMT/EMA skill mix.

We often understand what would be best for patient but don't feel we have the authority to act independently.

Example comments from ECPs are shown here.

I believe strongly in caring for EOL patients at home.

When [ECPs] are unavailable it appears that crews often feel it is "easier" to transport a person to hospital. Maybe that is due to the lack of education (and confidence) to be able to make tough decisions.

Taking time to seek better solutions is overlooked as referral pathways beyond hospice are not engaged.

As an ECP I feel that my training has given me a good understanding of end-of-life care.

ACP/shared goals of care

There were 79 (70%) comments in this section containing the phrase "end-of-life care" or similar. Many of these directly referenced ideas and problems around advance care planning.

All EAS personnel have access to patients' shared care records via phone calls to the clinical support hub, however, only paramedics, CCPs and ECPs have direct access. This creates a barrier to accessing a digital advance-care plan and other critical patient information needed to lead and deliver shared goals of care.

It was commonly felt that absence of an advance-care plan led to conflicting views around goals of care, resulting in transport to hospital.

I've found that all the different parties involved can be under different impressions on what's the best care going forward and can be a nightmare getting everything on the same page.

We discussed goals of care and administered the patient's own medications with good effect,

but I feel this could have been much, much better managed with interagency communication.

I find many families have not had the hard conversation and therefore still want to keep their relative alive as long as possible without excepting they are prolonging suffering.

The largest barrier in managing end-of-life care patients in the community as opposed to transporting them to hospital is the absence of a formal management plan.

…it seems people don't know what to do so call an ambulance.

Remote clinical advice

The utility of remote clinical advice appeared in 34/112 (30%) comments. Sources of clinical advice included the "clinical desk" as well as local palliative care and hospice services. The role of training was linked to clinical advice in 30% of comments.

I generally avoid calling the clinical desk for advice as they are not collegial.

Often, there is no one available for discussion/planning at Hospice.

I have used the clinical desk for after-hours medical advice for end-of-life medicine administration beyond my scope of practice, very successfully.

I would like end of-life wishes to be registered with Emergency Services in some way that we can call up [the] clinical desk and result be found within minutes.

…we need better shared pathways.

Non-core activity

There were ten comments from participants explicitly reporting that EOL care was not core to ambulance services, diverting them from their prime role as savers of life and limb. Due to being time poor, transport to ED was a better use of their time.

Paramedics are trained in the preservation of life. This requires a different mindset and skill set.

The primary role of an emergency ambulance is providing care to critically unwell patients.

I've found the increasing pressure on the ambulance service generally means we are unable to spend significant time with a patient and remain on scene.

Survey questions 4, 5 and 6

Question 4 of the survey asked whether documented wishes and preferences were easy to find and if they were useful in guiding care and treatment. Advance-care plans were reported as useful in 354 of 443 (80%) of responses, however 290 (65%) participants reported that these were often hard to find.

In 27 of the 65 (42%) comments available in this section, participants pointed out the lack of clarity especially around ambulance specific wishes.

Many patients have the paperwork but haven't worked through what they want or discussed with other family members.

In my 5 years I've yet to come across an advanced directive that has been correctly filled out and easy to find.

Particularly in rest-homes the advanced directive paperwork is shockingly inadequate.

Understanding the stages of ill-health and what it may appear like is vital for families.

Question 5 of the survey examined pastoral care. Participants were asked about the types of psychological support EAS personnel utilise following the death of a terminally unwell patient in their care (see Table 2).

The free-text part of this question resulted in 156 comments. Theme analysis showed that gaps in organisational support dominated in 73 (47%) of the comments pointing to the need for better formal support. Many offered solutions that included recognition/triggering of the need for organisation intervention, opt-out psychological assessments, programmed downtime, more and better constructed advance-care plans and better links to hospice.

EOL care isn't so much regarded as a traumatic event and as such isn't as actively supported.

Support is always available, however, you have to instigate it yourself which is often hard to do. I believe psychological support should be compulsory every 3 months regardless and funded...

...not be considered an incident type that would trigger a formal Peer Support follow up.

There is very little consideration how "normal" deaths impact us.

Trying your best to keep your patient comfortable while they slowly die can take more of a toll.

Probably better linked with hospice ... whether there were aspects that could be improved, what aspects we did well. We often leave a scene but don't know outcome.

Informal support through colleagues is important. Some viewed this as the best way of working through issues, while others felt that while important it was only one of several options. Thirty-five comments indicated that the respondents felt comfortable with themselves providing EOL care.

Personally, debriefing at the end of a job with colleagues who understand exactly what I am dealing with is more beneficial ...

Informal support from the people I work with and know and trust.

This is not one of the situations I would expect support from the service, unless something traumatic has happened.

Please accept if I don't want support I am not in denial.

...death is routine for us.

I don't feel there needs to be anything formal, it's caring for a person at the end of their life and if we can contribute positively to this then I feel it's a privilege to attend.

Question 6 asked for self-assessed cultural competence when caring for Māori and their whānau at or near the end of life. There were 441 responses; 254 (58%) indicated they either did not know or did not feel culturally competent. Of the 149 comments provided in this section, 119 (80%) highlighted the need for more education and training. Some felt that no education or resources have been offered while others felt that training was superficial and sometimes inaccurate. Some stated that cultural training is simply an extension of colonisation.

Comments also touched on equity, bias and racism. These themes were strongly linked with participants' thoughts on education such as involving local iwi, increasing the Māori workforce, mandatory competencies, web-based education and clinical placements. Equity was addressed by others who felt that recruiting a workforce more reflective of the general population is a worthy aspiration. Though the question was intended to address Māori, respondents also were careful to show that other cultures were important.

St John offer no formal competency training. To be competent all staff should be supported to actively reflect on their own prejudice and how this affects their treatment of minority patients.

I feel striving for cultural competence in a culture that is not our own, is a false label, and ultimately arrogant and potentially disrespectful.

Confusion is the most appropriate word here. So many different views.

I know we can ask, but it is often better to be informed on this first, so that you can ask from a position of being better informed.

As a white English girl, I am nervous about messing it up.

Generally, I would talk to the family and ask them to confirm/outline what they do in their culture so that

I do not offend anyone and assist them in the best possible way.

Talking with the whānau and asking what they would like is always good, taking great care with the body (regardless of culture) is so important…

Additional comments

The final section of the survey asked participants to write their thoughts on the topics surveyed. There were 255 comments from the 444 (57%) participants. Themes centred on education and training in 125 of 255 (49%), integration between ambulance and community services/hospice in 102 (40%) and the existence and visibility of care plans in 23/255 (9%).

Training on the cycle of dying patients and how they can sporadically improve, how to support family through this … would be helpful.

It can be difficult for ambulance staff to take a step back and change the mindset from "emergency care" to "end-of-life care".

I know people who would have rather died at home (were in hospice care/ hospital care at the time of death) but they didn't have this opportunity.

Rest homes have poor support for their staff in this area and so they look to us. Family expectations and to some degree rest home expectations are unreasonable…

It is unfortunate that too often, and probably that is the reason, we see pts at the end of life who have no plan or service in place yet… I find it hard to support the patient and/or the family the way they would wish.

Frequently we find patients dying are in that limbo period of having been discharged from hospital but no referral has been made to palliative care services, and no advanced care plan has been made.

Discussion

This is the largest survey of EAS examining EOL care in the community. Several small mixed methods studies in the UK and Australia have shown similar results that indicate gaps in training, education, patient-focussed care and staff support.[13–16] There have been no published studies in New Zealand.

EASs are increasingly the first point of acute care for people with advanced, incurable illnesses in the community. It is common for there to be no ACP in place and often there is limited access to palliative care. However contemporaneous, deliberate and visible planned EOL care is central to an informed decision process for ambulance crew. The common default is transport to ED.

Training and seniority play an important role in determining the type or appropriateness of acute EOL care. This survey shows significant gaps in both training around adequacy and visibility of care plans. The absence of clear, concise recorded patient wishes for care at the end of life is cause for concern.

As part of the deteriorating patient program, the New Zealand Health Quality and Safety Commission provides training in serious illness conversations and actively promotes shared goals of care.[6]

Lack of training in both palliative care and cultural safety were dominant themes. These ideas were not limited to training and education for EAS personnel but extended to the wider whānau and to ARC facilities.

There is an expressed desire for more organisational involvement in pastoral care—suggestions commonly focussed on triggers and enabling time for reflection.

It is noteworthy that more than 60% of EAS encounters nation-wide occur with non-registered ambulance personnel. Access to relevant digital health information for this large group is difficult and presents a barrier to accessing patient information that is critical to delivering focussed quality care to the EOL patient cohort.

Data made available by St John show that 9% of crew identify as Māori. Workforce structure better representing national demographics suggests a significant shortfall in Māori ambulance personnel numbers. Most participants either felt they were not culturally competent or did not know how to increase their knowledge in this area.

Strengths and limitations

Although this is the largest study of its kind, the proportion of EAS workforce who participated is approximately 14% of the total paid crew available at the time. This project was largely dependent on organisational promotion from within the St John and Wellington Free Ambulance services. Unfortunately, the recruitment period coincided with a peak in COVID-19 cases in Aotearoa New Zealand and both services stopped active promotion of the project. Promotion depended almost solely on unstructured communication to managers. The survey was disseminated via email and was also included in a national weekly bulletin that is delivered to all frontline operational staff. Potential reasons for poor participation may be a direct result of the time of the study. COVID-19 workload and ambulance personnel report being overwhelmed with workload and a high level of organisational communications at this time.

Responses were anonymised, which was likely to control for social desirability bias, encouraging open and frank comments. Potential biases include selection bias, where highly motivated individuals whose views may be strongly held are more likely to participate, and reporting bias, where the views of non-participants may vary considerably from those expressed in the survey. The effect of answers being influenced by questions already answered in survey was not controlled; the survey did not randomise the order of questions.

To simplify the survey, definitions for terms such as palliative care and cultural competency were not offered. We acknowledge that cultural competency and cultural safety are not interchangeable terms.

Conclusions

EAS personnel can expect to encounter an increase in calls relating to the support of patients with advanced disease who are at or near the end of their lives. There will inevitably be instances where an EAS is called out for people in their dying phase, even if no life-saving measures are possible or appropriate. Considerable organisational focus is required to prepare for this demand. Collaboration with local hospice palliative care services will assist in creating an environment where care and treatment decisions can be made that are safe, effective and in accordance with any expressed wishes, goals and preferences.

Regional inequities for EOL care appear to be on the basis of seniority, which tends to favour urban areas. The role remote clinical support for rural ambulance services could play is unclear and warrants further study.

Important themes to emerge from this work were the need for education and training in palliative and cultural safety, better community integration and support and for improvements in organisational pastoral care.

COMPETING INTERESTS
Nil.

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PATHA's vision for transgender healthcare under the current health reforms

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ABSTRACT

AIM: The Aotearoa New Zealand healthcare system does not adequately meet the needs of transgender people. Due to healthcare reforms and increases in funding and awareness of transgender health, the Ministry of Health has met with the Professional Association for Transgender Health Aotearoa (PATHA) to discuss ways to improve the healthcare system. We developed a vision for a transgender healthcare document to enable a process for our members to collaborate and to increase transparency about what advice PATHA has provided to the Ministry.

METHOD: Feedback from PATHA's committees was incorporated into a draft document, which was then sent to all PATHA members for further feedback and collaboration.

RESULTS: PATHA proposes improvements to transgender healthcare that are centred around a new transgender health resourcing hub, which should operate according to a Te Tiriti o Waitangi framework, provide national coordination of a distributed model of care, provide resourcing (including education) for primary care and actively work to increase provision and equity of gender-affirming surgeries. In order to be effective, the new resourcing hub would utilise peer health navigators, provide education and professional development, promote healing-focussed care and incorporate transgender community leadership and accountability.

CONCLUSIONS: These improvements would allow for the best practices from existing regional programmes to be implemented throughout the healthcare system. The proposed changes align with the goals of the healthcare reforms to make healthcare for transgender people more equitable, accessible and cohesive.

In Aotearoa New Zealand, transgender people should have full access to both gender-affirming healthcare and routine healthcare. Gender-affirming healthcare is care that facilitates peoples' abilities to embody, express and live in their gender. This includes endocrine and surgical procedures, hair removal, voice therapy and providing social and psychological support.[1] Not all transgender people require such care, but for those who do it is necessary to ensure their wellbeing.[2] Timely access to appropriate gender-affirming care reduces health inequities faced by transgender people, which could result in lower health costs for this population across individuals' lifespans.[3]

There is a significant unmet need for gender-affirming healthcare among transgender people in Aotearoa New Zealand. *Counting Ourselves, the 2018 Aotearoa New Zealand Trans and Non-binary Health Survey* found that this ranges from 19% for gender-affirming hormones (with rates of unmet need for hormones even higher among trans men [26%] and 14–25-year-olds [29%]) to 67% of transgender men having an unmet need for chest reconstruction surgery. Around half of transgender women had an unmet need for voice therapy (50%) and feminising genital surgery (49%).[4]

There is a growing demand for gender-affirming healthcare among transgender people,[5] but often there are barriers to this care, including unavailability. Transgender people often have to pay significant individual healthcare costs, as gender-affirming healthcare is not always accessible through public healthcare systems. This can result in many people being unable to access the care they need, and some may fundraise for this essential healthcare through donations from friends, whānau and transgender communities.[6]

Even when services are available in the public healthcare system, they are often not sufficient to meet demand due to funding and capacity limitations or a lack of trained healthcare providers.

Long waiting lists for public endocrinologists or psychologists can delay access to gender-affirming hormones or puberty-delaying medications for unacceptable lengths of time, or require individuals to pay for private consultations. Gender-affirming surgeries in the public sector suffer from chronically under-estimating demand, under-resourcing, lacking training in gender-affirming care and having to compete for priorities with other elective surgeries. We are not aware of any plan to address the substantial unmet need; the current health reforms and the creation of Te Whatu Ora – Health New Zealand and Te Aka Whai Ora – Māori Health Authority provide an opportunity to address this in a coordinated manner.

In 2021 and 2022, members of the Professional Association for Transgender Health Aotearoa (PATHA) met with the Associate Minister of Health Honourable Dr Ayesha Verrall, and Ministry of Health officials. We created our Vision for Transgender Healthcare document to create a process for PATHA members to collaborate on developing the advice and recommendations that PATHA made to the Minister and the Ministry and to share this information with the wider public. This article is an adaptation of the full document[7] to inform health professionals across Aotearoa of PATHA's vision for how transgender healthcare can be improved in this country, particularly in light of current health reforms.

Method

The PATHA Vision for Transgender Healthcare document began with an initial outline that was sent to members of the PATHA Executive, and its Education, and Policy and Advocacy Committees for feedback. After their feedback was incorporated, a draft of the full document was developed and was sent to all of the approximately 200 PATHA members for feedback, with their comments then incorporated into the final version.

The goals and elements of this strategy have been informed by Trans Care BC, which is an information and resourcing hub for transgender people in the public health system of British Columbia, Canada. Trans Care BC provides information about transgender health, helps transgender people with accessing healthcare and navigating the healthcare system, and provides clinical support to healthcare professionals through education, resources and clinical standards. Its programme aims to bring "*gender-affirming care closer to home wherever possible*" and to support equity and accessibility of care.[8]

Results

PATHA would like to see clear requirements, resourcing and accountability for Aotearoa's new healthcare system to provide accessible gender-affirming healthcare, including at a minimum: puberty blockers, fertility preservation, gender-affirming hormones, psychosocial support, hair removal, voice therapy and gender-affirming surgeries. This would include a clear expectation of timely access to care, without the current "postcode lottery" across regions for gender-affirming healthcare.

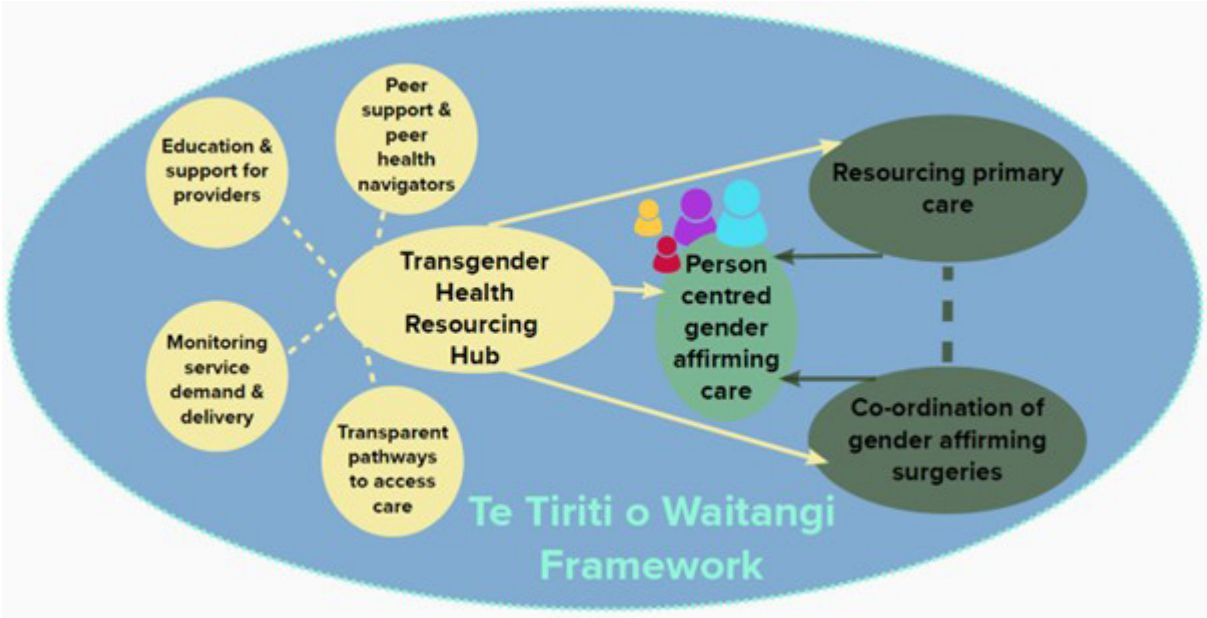
The Ministry of Health definition of equity "*recognises different people with different levels of advantage require different approaches and resources to get equitable health outcomes*".[9] PATHA recommends that a new transgender healthcare resourcing hub be established with an aim to support the healthcare system to provide more equitable, person-centred, accessible and cohesive healthcare for all transgender people, regardless of where they live in Aotearoa New Zealand. This hub would not provide clinical care directly, but instead focus on navigation, coordination and resourcing for this care in the new health system. As well as national coordination, this hub could include regional expertise for local coordination and initiatives provided across regions. In order to ensure equity of access to care, it is important that the new hub monitors the extent of both demand and provision of all types of gender-affirming care.

We are proposing a hub-and-spoke model where the transgender health resourcing hub could assist with national coordination of a distributed model of care, where some care—such as gender-affirming hormones—is delivered locally, and other care—such as surgery—is delivered regionally or nationally.

Te Tiriti o Waitangi framework

Our vision for transgender healthcare includes a Te Tiriti o Waitangi framework. We aim to align with the goals of the current health reforms to work in partnership with Māori, honouring Te Tiriti o Waitangi, and achieving health equity for all people in Aotearoa New Zealand, particularly Māori.[10] We propose that the transgender health resourcing hub should have a steering group that includes significant Māori and takatāpui

Figure 1: Elements of the proposed vision for transgender healthcare under the current health reforms.



expertise and leadership. The healthcare system, including Te Aka Whai Ora, should also resource Kaupapa Māori and Pasifika healthcare services to provide high-quality gender-affirming and general healthcare and be grounded in Māori and Pasifika knowledge, models of healthcare and health promotion.[11,12] Within such frameworks, person-centred care is both holistic, including all relevant aspects of one's ola lelei (wellbeing) and collective involving those in a person's world who are key to their gender-affirmation journey, such as whānau (whakapapa-based and kaupapa-based), kāinga (extended family) and matakeinanga (wider community).

Our vision for transgender healthcare under the current health reforms is illustrated in Figure 1. This includes grounding in a Te Tiriti o Waitangi framework.[13] Each element of the vision is discussed below.

Resourcing and supporting primary care

Currently, gender-affirming hormones are prescribed by a variety of health professionals in a range of primary and secondary care settings in Aotearoa New Zealand.[4] Pathways to access gender-affirming hormones vary markedly across regions. In some regions, there has been a shift towards primary care for gender-affirming care to better meet increasing demand and the needs of transgender communities.[14,15]

Distributing gender-affirming care among a range of primary care services will make it more likely that the diverse needs of transgender people are met. Population-based research has found that at least 1.0% of adolescents[16] and 0.8% of adults[17] in Aotearoa are transgender. The demand for gender-affirming hormones is increasing due to more people feeling comfortable to explore their genders. A model of care in which initial access to gender-affirming hormones is only provided by centralised services (whether in primary care or secondary care) risks becoming oversubscribed and could perpetuate the idea that health professionals need specialist expertise to provide care to transgender people. Primary care should be an ideal place for providing gender-affirming healthcare, as this type of care may be interlinked with other areas of health and wellbeing, and primary care clinicians are experts in whole life experience. Additionally, primary care providers are part of patients' home communities or with the community service providers that best fit their needs and are familiar with their other health needs, such as hauora Māori and Pasifika health providers and Youth One Stop Shops (YOSSs). Primary care providers' scopes of practice vary, and the healthcare needs that transgender people have are also varied. In support of gender-affirming care being provided in primary care, the latest version of the World Professional Association for Transgender Health Standards of Care states that if primary

care providers are "*competent to deliver similar care for cisgender patients, they should develop competency in caring for [transgender] patients*".[1]

Research has shown that assessments by mental health professionals for gender-affirming hormones and surgeries can be experienced as a requirement to "prove" one's gender, leading to people saying what they think the provider wants to hear.[18] With sufficient support, education or knowledge of the intervention, any qualified doctors and nurse practitioners can assess whether someone meets requirements to access gender-affirming hormones or to be referred for surgeries.[1,2] Because they are likely to be more aware of a person's health needs and history, primary care prescribers with an established and ongoing relationship with patients currently in their care may be the best people to assess capacity to give informed consent for gender-affirming hormones, just as they may be for other medical treatments and care. If mental health professionals are not required to assess people for gender-affirming hormones or surgeries, they will have more time to work with those transgender people who require mental health support. PATHA would like to see cost barriers removed for transgender people choosing to access such mental health support. We also call for more education for mental health professionals, including the growing primary mental health workforce, to build cultural safety when delivering care to transgender people.

The transgender health resourcing hub could support primary care prescribers to be able to initiate and provide ongoing prescriptions for gender-affirming hormones for adults who do not have complex physical or mental health needs. Developing this capacity nationally may need to occur in steps, starting with recognition and support for GPs and nurse practitioners who have a special interest in transgender healthcare, including strengthening clinical peer support networks.

Gender-affirming care should be accessible and free, based on informed consent and tailored to individualised needs and goals. This may include psychosocial support, access to peer support, gender-affirming hormones and pathways for referrals to secondary care services where necessary. It is essential that primary care providers have full resourcing in order to provide such gender-affirming care. This includes financial support for extended appointments with clinicians where needed. The new transgender healthcare resourcing hub should play a key role in providing education and training for primary care staff, as well as funding or employing clinicians as clinical leaders, acting as a point of contact for primary care clinicians to readily access support for providing this care.

The transgender health resourcing hub would continue to support secondary care services and specialised primary care services to provide additional support for gender-affirming care where needed, such as for children and adolescents, as well as for adults with complex physical or mental health needs. This could be through both local referral pathways and liaising with more specialised services. PATHA recommends that existing provision for more specialised primary and secondary care services continues.

Resourcing gender-affirming surgeries

Genital surgeries

The national Gender Affirming (genital) Surgery (GAgS) Service requires much greater funding to meet the population's needs. With funding for only 14 surgeries per year, GAgS would take over 27 years to be able to provide surgery to all of its 389 current active referrals as at December 2022.[19] The *Counting Ourselves* study conducted in 2018, when these surgeries were part of the High Cost Treatment Pool, found that most people were not aware that this service existed and only 15% of *Counting Ourselves* participants needing genital surgeries had applied to the service, with most who did not apply saying it was not worth it because of the length of the waitlist.[4]

PATHA recommends that Te Whatu Ora – Health New Zealand and Te Aka Whai Ora – Māori Health Authority review the GAgS service and follow international models of best practice for surgical services that include a multi-disciplinary team of surgeons, anaesthetists, hair removal technicians, clinical nurse specialists, physiotherapists, mental health professionals and peer health navigators. This team would provide the full range of services needed for surgical care, including psychosocial pre- and post-operative support for those receiving or waiting for these surgeries.

Other gender affirming surgeries

There is a high level of unmet need for other (non-genital) gender-affirming surgeries in New Zealand, such as chest reconstruction, breast augmentation, facial feminisation, voice surgery, orchiectomy and hysterectomy/oophorectomy.[4]

Access to these surgeries in the public health system is very limited, and service provision varies by region.[20] Some local districts have applied criteria for gender-affirming surgeries that are more restrictive than international and national best practice, which may lead to inequitable outcomes.

PATHA recommends that the new healthcare system and transgender healthcare resourcing hub provide comprehensive pre- and post-operative care for people accessing all types of gender-affirming surgeries, and also post-surgical care for people who pay privately to go overseas for these medically necessary surgeries. We would like this to include funded management for future complications from these surgeries. In addition, the provision of all gender-affirming surgeries, including genital (bottom), chest (top) and facial surgeries, should be increased to meet the rising demand. The new system should also provide national coordination for gender-affirming surgeries, ensure transparent pathways to care and equity of access to surgeries across districts, and fund appropriate multi-disciplinary professionals to provide clinical opinions or support patients to meet any clinical requirements to access gender-affirming surgeries.

Enabling strategies

To achieve full access to appropriate care, a transgender healthcare resourcing hub should be created with the following enabling strategies.

Peer health navigators and support

Not knowing where to go to access gender-affirming care is a significant barrier in the current healthcare system. *Counting Ourselves* survey participants reported that not knowing where to go was the most commonly reported barrier for hormones (40%), and it was the second most reported barrier, after cost, for most surgeries.[4] Healthcare navigators are essential to break down this barrier. Regional gender-affirming care services are increasing turning to peer healthcare navigators and support workers to meet these needs in a way that has relatively lower costs.[15]

PATHA recommends that the new transgender healthcare resourcing hub should establish a national network of peer health navigators to provide staff in peer navigator roles with adequate support, integration with other healthcare services and, where needed, training towards accredited qualifications.

Transgender people who have access to peer support are likely to benefit from improved mental health and personal growth. Where this is provided, peer support may be best contracted out to community organisations. We recommend that people working in peer support roles should have access to the training, support and supervision that they need, including instruction in clinical guidelines, communication skills, maintaining confidentiality, setting boundaries, appropriate information disclosure and practising self-care. They should also have links with health services (e.g., referral pathways to mental health services) for situations where these are required. We also recommend scholarships for Māori and other groups that face additional healthcare access barriers to ensure the network of peer navigators and support workers meets the needs of diverse transgender communities.

Education, resources and professional development

Transgender people are more likely to delay or avoid access to healthcare due to anticipated discrimination, and are more likely to receive unsatisfactory care.[4,21–23] Over a third of transgender people in Aotearoa New Zealand had avoided seeing a doctor when they needed to due to worries about disrespect or mistreatment.[4] Health services may not be effective or safe enough for transgender people due to inadequate staff training and exclusionary policies and environments.[4,20] Providing healthcare that is culturally safe and inclusive for transgender people is the responsibility of any health professional, regardless of speciality, and not just those with specialist knowledge in transgender health.

PATHA recommends that the new healthcare system and transgender healthcare resourcing hub should provide education and training for all healthcare staff on transgender cultural safety and awareness; work with professional bodies, medical colleges, and tertiary institutions to include transgender cultural safety and awareness in professional healthcare curricula; and provide clinical mentoring and supervision for health professionals working in the field of transgender health. In addition, the healthcare system should promote cultural safety in services for transgender Māori and their whānau, as well as for transgender people from all ethnic minority cultural backgrounds.

Healing-focussed care

Transgender people have long been pathologised by the medical system, with their identities being labelled as a mental disorder. However, this is

changing, with gender-affirming healthcare now being seen as part of the range of sexual healthcare needs related to bodily autonomy in the latest revision of the International Classification of Diseases.[24]

Many healthcare environments, policies and systems continue to be harmful for transgender people. Transgender people are often still pathologised and their identities are not respected, and they often have to deal with unsafe or stressful gender-segregated spaces in healthcare settings.[4,22] PATHA recommends a new resourcing hub that advises on healthcare service design considerations such as removing assumptions about gender in some types of care (e.g., maternity care) and in gender-segregated spaces. There is a lack of inclusive data collection and management practices,[25] which can cause problems with referrals and other services. The new healthcare system should improve data management systems to better protect the privacy, safety and continuity of care for transgender people.

Transparency, accountability and transgender community leadership

There is currently very little publicly accessible, clear information about what gender-affirming care is available in the healthcare system and how to access it.[20] This can lead to people needing to self-advocate to receive essential medical care. While peer health navigators could assist with information provision and advocacy support, it is also important that the healthcare system is publicly transparent about services and provides accessible information about pathways to access gender-affirming healthcare.

PATHA recommends that the new healthcare system should partner with transgender communities and their organisations to design and operate the new transgender health resourcing hub. The hub should be led by a steering group of transgender community leaders, and undergo a programme of education and training to build capacity for transgender people in leadership roles. The new healthcare system should be transparent and accountable to transgender communities, and be publicly visible in the communities in which it serves. This includes having measurable outcomes, information that is publicly accessible in a range of domains (e.g., web pages, flyers for community organisations) and clear contacts for clarification of services available in local districts.

Conclusion

The present healthcare system does not adequately meet the needs of transgender people. With the current health reforms, we need to make healthcare for transgender people more people-centred, equitable, accessible and cohesive. We propose that this is done by creating a new transgender health resourcing hub that operates under a Te Tiriti o Waitangi framework, provides national coordination of a distributed model of care, actively works to resource primary care and provides support for gender-affirming surgeries. For the new resourcing hub to work effectively, it should utilise peer health navigators, education and professional development, healing-focussed care and transgender community leadership and transparency.

In essence, PATHA is proposing that this new healthcare system take the best things that are occurring regionally and provide coordination of these in a national hub. Examples of current regional good practice include transgender leadership having been crucial for the redesign of gender-affirming healthcare services in Waitaha Canterbury and, in the Northern Region, Hauora Tāhine providing clear and transparent pathways available online for people, employing a key worker to help people navigate access to gender-affirming care, and this service being actively involved in local rainbow community events. Much of what we recommend is already occurring in some regions. Designing a national hub will allow us to take the best practices we are seeing and implement them throughout the whole country.

COMPETING INTERESTS
Nil.

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Genetic discrimination by insurance companies in Aotearoa New Zealand: experiences and views of health professionals

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ABSTRACT

AIMS: Genetic discrimination in insurance is a significant clinical, research and consumer issue. Recently, the Australian life insurance industry introduced a partial moratorium on the use of genetic test results. However, in Aotearoa New Zealand, both life and health insurers can still use genetic results legally to discriminate against applicants. We aimed to document experiences and concerns of New Zealand-based health professionals (HPs) around the potential misuse of genetic test results for insurance purposes.

METHODS: We administered an online survey to New Zealand HPs who discuss genetic testing with patients, their experiences regarding the use of genetic test results in insurance and views on regulation.

RESULTS: Twenty-three New Zealand HPs responded, 15 of whom worked in genetics clinics, representing >60% of the total New Zealand clinical genetics workforce. Eleven respondents reported having patients who experienced adverse outcomes related to insurance based on genetic results. Respondents reported patients sometimes/often delayed (n=11) or refused (n=4) genetic testing due to insurance concerns. Over 80% of those who answered (n=17/21) believe insurers' use of genetic results should be legally regulated.

CONCLUSION: New Zealand HPs have concerns about insurance companies using genetic test results in underwriting, including the effect on patients, and strongly believe government legislation is required.

Genetic discrimination (GD) is defined as "*differential treatment of asymptomatic individuals or their relatives on the basis of real or assumed genetic differences or characteristics*".[1] GD in insurance underwriting is a significant clinical, research and consumer issue. International research has demonstrated that concerns regarding insurance implications deter people from clinically indicated genetic testing and involvement in research.[2–6] Health professionals (HPs) also express concerns regarding the impact of GD on patients.[7–10]

Many countries have banned or restricted the use of genetic test results in insurance through various policy mechanisms.[11–12] Canada's *Genetic Non-Discrimination Act (2017)* bans the use of genetic test results by any entity providing goods or services,[12] meaning the use of genetic test results is prohibited for both health insurance and life insurance underwriting (except where results that are favourable to the applicant are disclosed voluntarily—for example, where a patient has *not* inherited a disease-causing familial DNA variant). In the USA, the *Genetic Information Non-Discrimination Act (2008)* prohibits health insurers from using genetic test results (with some exclusions), though it does not apply to life insurance. Recently, the US state of Florida has introduced a law prohibiting life insurers from using predictive genetic test results in underwriting.[13] Since 1997, Europe's Convention on Human Rights and Biomedicine has banned discrimination on the basis of genetic test results, and in 2016, the Council of Europe adopted Recommendation CM/Rec(2016)8, which requires Member States to take steps to prevent discrimination in insurance contracts, including on grounds of genetics.[14] Since 2001, an agreement between the Association of British Insurers and the UK government has banned health and life insurers from using genetic results in underwriting, with one exception—predictive genetic test results for Huntington disease for death cover policies worth over £500,000 (~$950,000 NZD). The UK Code on Genetic Testing and Insurance[15] is indefinite and is reviewed every 3 years.

In Australia, health insurers cannot use genetic results (or other risk information) to deny cover

under the *Private Health Insurance Act 2007* (Cth).[14] However, life insurers can legally discriminate on the basis of genetic test results under section 46 of the *Disability Discrimination Act 1992* (Cth). Following a 2017 Australian Parliamentary Joint Committee (PJC) inquiry into the life insurance industry, the PJC recommended that a moratorium be implemented in Australia (similar to the UK moratorium), and if necessary, legislation may follow.[16] Although the Australian Government has not responded to the PJC recommendations, in July 2019 the life insurance industry introduced a partial moratorium on the use of genetic results in life insurance.[17] The moratorium is self-regulated by the Financial Services Council (FSC), the regulatory body for Australian life insurers,[18] is not legally enforceable and applies only to life insurance policies up to certain financial limits.

In Aotearoa New Zealand, both life and health insurance companies can still use genetic test results in underwriting, which can lead to GD. The *New Zealand Human Rights Act 1993* (HRA) prohibits discrimination on the grounds of disability, but an exception in s48 of the HRA allows discrimination in both life and health insurance policies, if based on actuarial or other data on which it is reasonable to rely.

New Zealand has a small population (~5.1 million in 2021[19]) and clinical genetics workforce. Although New Zealand HPs who discuss genetic testing with patients must discuss potential risks including insurance implications,[20] little research has been conducted into the experiences or views of New Zealand HPs regarding GD in insurance. A survey conducted in 2017,[7] which included New Zealand HPs, was not tailored to New Zealand, and New Zealand data were not published separately. With Australia and many other countries revisiting this issue recently,[21–22] it is critical for New Zealand to now consider its position. In 2021, a group of clinicians, academics, ethics and law experts, patients, and representatives from Indigenous communities formed a collaboration called Against Genomic Discrimination Aotearoa; AGenDA. This group (of which the authors of this paper are members) has documented anecdotal experiences and views of New Zealand HPs,[23,24] however, there is a paucity of published data. This study represents the first dedicated study of the views and experiences of New Zealand HPs about the use of genetic test results in insurance underwriting.

Methods

HPs in Australia and New Zealand were surveyed together as part of a combined study, with slight differences in the survey accessed by each. The results from the Australian survey have been published previously, and the methods of survey development and recruitment are described in that publication.[25] The survey addressed participant demographics, knowledge and training associated with insurance and genetics, general views regarding regulation of the insurance industry, and experience of patient attitudes and behaviours in response to perceived GD. The survey was developed following consultation with clinical and research professionals, as previously validated scales did not exist. A blank copy of the survey is included as Appendix 1.

Sampling and recruitment

The eligible population was qualified HPs working in a New Zealand health service who discuss genetic testing with patients. This encompassed clinical geneticists and genetic counsellors, as well as other health professionals working outside clinical genetics services who organise genetic testing (including but not limited to nurses, cardiologists and oncologists). Recruitment strategies utilised included newsletters emailed via the Human Genetics Society of Australasia (HGSA) and Australasian Society of Genetic Counsellors (ASGC), social media advertisements and snowballing via direct emails to professional contacts to assist with dissemination.

Survey development and data collection

We conducted an online survey using REDCap software,[26] adapted from the Australian survey[25] to account for differences in regulation of this issue. Most questions used closed-ended Likert scales, although several open-ended questions allowed for additional information via free text. The survey was open from April–June 2020.

Data analysis

We used descriptive analysis to report aggregate responses to closed-ended questions, grouped by profession. Statistical analysis of differences between groups was not possible due to the small sample size. Responses to open-ended questions were grouped into key thematic categories and reported using representative quotes.

Ethics approval

This project was granted approval by the Monash University Human Research Ethics Committee on 11 March 2020, ID number 22576, and was performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki.

Results

Respondents

Overall, 23 New Zealand health professionals (HPs) who discuss genetic testing with patients responded to the survey (Table 1). The survey was completed online, and some respondents did not complete all questions—"n" values are provided to clarify the number of respondents for each question.

Given the diverse methods of recruitment, a response rate is difficult to estimate. However, the respondents are grouped into two categories—genetic HPs and non-genetic HPs. Genetic HPs include genetic counsellors (GCs) and clinical geneticists (CGs). Non-genetic HPs include other qualified HPs who discuss genetic testing with patients, such as oncologists. At the time of data collection, there were 9 CGs and 17 GCs (26 total) employed by Genetic Health Services New Zealand (GHSNZ), meaning the respondents to this survey represented more than half of the known clinical genetics workforce in New Zealand (n=15/26) and can be considered representative of that group. Further, when the minimum years of experiences across the respondents are added up, the genetics HPs who responded cumulatively represent a minimum of 243 years of professional experience. The non-genetics HPs are likely a small fraction of HPs who discuss genetic testing with patients in New Zealand.

Three main themes are presented from the data: potential barriers to genetic testing due to insurance discrimination fears; a need for greater regulation of the use of genetic test results in insurance underwriting; and concerns about professional training and awareness.

Barriers to genetic testing and surveillance

Over half of the HPs surveyed (n=11/21) reported that they had observed patients *delaying* genetic testing "often or sometimes" due to life, income or trauma/critical illness insurance concerns. Further, 4/21 participants reported that they had observed patients *refusing* genetic testing sometimes for this reason (Table 2).

Over half of participants (n=11/21) also reported patient/s telling them about an adverse insurance outcome based on genetic test results (Table 3). They report applications for both health and life insurance that were denied, had premiums increased, and/or had exclusions applied. Further, HPs report applicants being required to take a genetic test before being offered insurance policies, and even insurers refusing to pay out claims to family members due to genetic testing carried out on asymptomatic individuals after their death.

When asked "*what, if any, would be the benefits of a moratorium on genetic testing and life insurance in New Zealand?*" some participants considered this would provide reassurance to people considering genetic testing and reduce the potential for discrimination against patients and families.

> *"More people would be comfortable coming forward for medically necessary genetic testing." [CGC, 6–10 years of experience]*

> *"Reassurance for patients that genetic testing that would allow lifesaving intervention for the wider family will not open them up to discrimination. With genetic testing in place, many of their clients will be healthier than if genetic testing isn't possible. Knowing about a genetic condition may allow surveillance, or planning." [CGC, >20 years of experience]*

Participants were also able to provide additional comments in free text. In these comments, further concerns were expressed about GD and reduced access to genetic testing (because of GD fears) that could provide important health information.

> *"I think there should be a certain amount of cover people can get regardless of their genetics. People should not be discriminated against because of their genetic status, which they had no control over." [AGC, 0–5 years of experience]*

> *"Patients decline testing that can potentially save lives in the wider family, around concerns for insurance coverage. Because genetic testing in an affected individual is needed to provide predictive testing to unaffected relatives, this concern is detrimental to the health of the wider family."*

Table 1: Participant demographics (n=23).

Demographic	Category	Number (%)
Location	New Zealand	23 (100)
	Australia	0 (0)
Profession	Associate genetic counsellor (AGC)	5 (22)
	Certified genetic counsellor (CGC)	8 (35)
	Clinical geneticist (CG)	2 (9)
	Non-genetic HP	7 (30)
	Not stated	1 (4)
Years of experience	0–5 years	5 (22)
	6–10 years	5 (22)
	11–15 years	4 (17)
	16–20 years	4 (17)
	>20 years	5 (22)
Average number of appointments with patients considering testing (per fortnight)	0–5	7 (30)
	6–10	10 (43)
	11–20	5 (22)
	No answer	1 (4)
Area of practice	Public only	18 (78)
	Private only	0 (0)
	Public and private	4 (17)
	No answer	1 (4)
Area of genetic testing*	Diagnostic testing—adults	19 (83)
	Diagnostic testing—children	12 (52)
	Predictive testing—adults	19 (83)
	Predictive testing—children	12 (52)
	Carrier testing	14 (61)
	Prenatal testing	15 (65)
	Secondary findings—clinical	15 (65)
	Secondary findings—clinical	3 (13)

* More than one area could be selected.

Table 2: Patient attitudes, behaviours and reported experiences.

Domain	Question	Responses	Genetics HPs (%)	Non-genetics HPs (%)	Total (%)*
How often do you estimate patients delayed predictive testing (n=21)	Due to life, income, or trauma/critical illness insurance concerns?	Never	0/15 (0)	0/6 (0)	0/21 (0)
		Rarely	6/15 (40)	4/6 (67)	10/21 (48)
		Sometimes	8/15 (53)	0/6 (0)	8/21 (38)
		Often	1/15 (7)	2/6 (33)	3/21 (14)
	Due to travel insurance concerns?	Never	4/15 (27)	3/6 (50)	7/21 (33)
		Rarely	10/15 (67)	3/6 (50)	13/21 (62)
		Sometimes	0/15 (0)	0/6 (0)	0/21 (0)
		Often	1/15 (7)	0/6 (0)	1/21 (5)
How often do you estimate patients refused predictive testing (n=21)	Due to life, income, or trauma/critical illness insurance concerns?	Never	2/15 (13)	0/6 (0)	2/21 (10)
		Rarely	10/15 (67)	5/6 (83)	15/21 (71)
		Sometimes	3/15 (20)	1/6 (17)	4/21 (19)
		Often	0/15 (0)	0/6 (0)	0/21 (0)
	Due to travel insurance concerns?	Never	5/15 (33)	4/6 (67)	9/21 (43)
		Rarely	10/15 (67)	2/6 (33)	12/21 (57)
		Sometimes	0/15 (0)	0/6 (0)	0/21 (0)
		Often	0/15 (0)	0/6 (0)	0/21 (0)
Have patient/s told you about having had an adverse insurance outcome on the basis of genetic test results? (For example, having difficulty obtaining a policy, having an increased premium or having a policy application denied)? (n=22)		Yes	9/15 (60)	3/7 (43)	12/22 (55)
		No	6/15 (30)	4/7 (57)	10/12(45)

* The survey was completed online and some respondents did not complete all questions—"n" values are provided to clarify the number of respondents for each question.

Table 3: Reported adverse outcomes of testing on insurance: participant quotes.

Quotation	Participant
"They have had difficulty obtaining policies. Difficulty accessing cover because of the ambiguous language in policies or policies not covering preventative measures. Applications being denied because no testing has been completed."	ID1, AGC, 0–5 years of experience
"Denied health or life insurance."	ID6, CGC, >20 years of experience
"Application denied, exclusions and increased premiums."	ID7, CGC, 16–50 years of experience
"Many people have reported problems with accessing health insurance or increased premiums."	ID8, CGC, 6–10 years of experience
"Individuals have contacted our service prior to having genetic testing, saying that their insurance company is asking them to have a genetic test prior to obtaining a policy."	ID9, CGC, 6–10 years of experience
"Patients have tried to obtain insurance policies prior to genetic testing and was declined. Others have tried after testing and have experienced a higher premium or have been declined."	ID10, CGC, 0–5 years of experience
"Risk reducing refused, cover refused, increased premiums."	ID11, CGC, 16–50 years of experience
"BRCA1 carrier who was declined coverage for any cancer diagnosis, not just BRCA1 related cancers. Patients have chosen to go without insurance due to cost of premiums."	ID13, CGC, >20 years of experience
"Multiple family member of a LQT pedigree screened and DNA tested that owned farms had increased premiums."	ID18, non-genetics HP, >20 years of experience
Advised that life insurance wasn't going to pay out on a death because of post-mortem genetic testing (no pre-existing illness)."	ID20, non-genetics HP, 11–15 years of experience

Table 4: Regulation and moratorium.

Question	Responses	Genetics HPs (%)	Non-genetics HPs (%)	Total (%)*
Based on your professional experience, how do you feel about a moratorium with these terms as a solution to genetic discrimination in life insurance? (n=21)	Very satisfied—this is the ideal solution	1/15 (7)	0/6 (0)	1/21 (5)
	Somewhat satisfied—this is a pretty good solution	10/15 (67)	4/6 (67)	14/21 (67)
	Somewhat dissatisfied—the solution could be better	4/15 (27)	1/6 (17)	5/21 (24)
	Very dissatisfied—the solution should be much better	0/15 (0)	1/6 (17)	1/21 (5)
In your opinion, how should insurers' compliance with such a moratorium on using genetic test results in life insurance be regulated? (n=21)	Self-regulation by the life insurance industry (FSC)	2/15 (13)	2/6 (33)	4/21 (19)
	Regulation through legally enforceable rules	13/15 (87)	4/6 (67)	17/21 (81)
	Other	0/15 (0)	0/6 (0)	0/21 (0)
In the UK, there is a moratorium that involves a formal agreement between the UK government and the life insurance industry. Do you think a formal agreement between the New Zealand Government and industry (Financial Services Council) is required on this issue in New Zealand? (n=21)	Yes	13/15 (87)	5/6 (83)	18/21 (86)
	No	2/15 (13)	1/6 (17)	3/21 (14)
Do you think the New Zealand government should introduce legislation to regulate the use of genetic test results in life insurance? (n=21)	Yes	14/15 (93)	3/6 (50)	17/21 (81)
	No	1/15 (7)	3/6 (50)	4/21 (19)

* The survey was completed online and some respondents did not complete all questions—"n" values are provided to clarify the number of respondents for each question.

Table 5: Awareness, training, knowledge, professional practice.

Question	Responses		Genetics HPs (%)	Non-genetics HPs (%)	Total (%)*
Has your health service provided, or have you attended, any training or information sessions regarding the moratorium and insurance implications of genetic testing? (n=23)	Yes, formal training		0/15 (0)	0/8 (0)	0/23 (0)
	Yes, information sessions		4/15 (27)	1/8 (13)	5/23 (22)
	No		11/15 (73)	7/8 (87)	18/23 (78)
How well do you feel you now understand insurance implications for individuals undergoing genetic testing? (n=22)	Extremely well		0/15 (0)	1/7 (14)	1/22 (5)
	Reasonably well		10/15 (67)	2/7 (29)	12/22 (55)
	Not particularly well		5/15 (33)	3/7 (43)	8/22 (36)
	Not well at all		0/15 (0)	1/7 (14)	1/22 (5)
Do you feel you have sufficient knowledge about the current insurance implications of genetic testing to properly advise patients? (n=22)	Yes		7/15 (47)	2/7 (29)	9/22 (41)
	No		8/15 (53)	5/7 (71)	13/22 (59)
Number of knowledge questions answered correctly (n=21) (for question-specific data see Appendix 2)	0	"Poor knowledge"	0/15 (0)	1/6 (17)	1/21 (5)
	1		1/15 (7)	1/6 (17)	2/21 (10)
	2	"Average knowledge"	3/15 (20)	1/6 (17)	4/21 (19)
	3		5/15 (33)	3/6 (50)	8/21 (38)
	4	"Good knowledge"	4/15 (27)	0/6 (0)	4/21 (19)
	5		2/15 (13)	0/6 (0)	2/21 (10)

Table 5 (continued): Awareness, training, knowledge, professional practice.

Question		Responses	Genetics HPs (%)	Non-genetics HPs (%)	Total (%)*
Is there a statement about insurance implications... (n=22)	On your consent form, where you have a specific form for predictive genetic testing in adults? (n=7)	Yes	3/4 (75)	2/3 (67)	5/7 (71)
		No	1/4 (25)	1/3 (33)	2/7 (29)
	On your consent form, where you have a standard form for all genetic testing? (n=15)	Yes	11/11 (100)	2/4 (50)	13/15 (87)
		No	0/11 (0)	2/4 (50)	2/15 (13)

* The survey was completed online and some respondents did not complete all questions—"n" values are provided to clarify the number of respondents for each question.

[CGC, >20 years of experience]

Need for increased regulation

Over 80% (n=17/21) of HPs considered the New Zealand Government should introduce legislation to regulate use of genetic results in life insurance underwriting (Table 4). In free-text comments, some HPs specifically mentioned this should also extend to health insurance regulation.

> *"…my main concern is access to health insurance, but protection against insurance discrimination for all insurance types would be important." [CGC, 6–10 years of experience]*

Similar concerns about applicability to health insurance arose when asking about the introduction of a moratorium in New Zealand similar to that in Australia.

> *"This is a great solution for life insurance, however for New Zealand main concerns I hear from patients are around health insurance access. This is a good solution for Australia but would not address the issues here in NZ." [CGC, 6–10 years of experience]*

When asked about introduction of a moratorium in New Zealand, over 85% (n=18/21) of HPs agreed New Zealand should introduce a formal agreement between the New Zealand Government and the insurance industry against genetic discrimination in insurance as a regulatory option (Table 4). For some, the recent introduction of a moratorium in Australia was seen as progress that should be followed in New Zealand:

> *"I think it is something that urgently needs to be reviewed in New Zealand and hopefully we can use the example Australia has set." [AGC, 0–5 years of experience]*

Of 13 HPs who answered a question regarding what, if any, would be the benefits of a moratorium on genetic testing and life insurance in New Zealand, most noted either reducing barriers to testing or reducing discrimination.

> *"More people would be comfortable coming forward for medically necessary genetic testing." [CGC, 6–10 years of experience].*

> *"Huge benefits and protection for our New Zealand patients. At the moment it is unclear how exactly genetic results are being used and I think there is massive scope for discrimination that is not recognised. Insurance companies are also using a lot of misinformation and unfairly penalising families." [AGC, 0–5 years of experience]*

Of 8 HPs who answered a question about the limitations of a moratorium, issues mentioned included the lack of health insurance coverage (as noted above), the financial limits applied, lack of regulation and continued discrimination on other grounds.

Although a minority (n=4/21) felt self-regulation by the life insurance industry (FSC) was appropriate, most (n=17/21) thought insurers' compliance should be regulated through legally enforceable rules (Table 4). In free-text comments, a view was frequently expressed that self-regulated restrictions would be an improvement on the status quo, rather than the ideal solution.

> *"Government regulation would be good, but self-regulation would be better than the current [situation]." [CGC, >20 years of experience]*

A minority of HPs (n=4/21) did not support the introduction of legislation—some expressed a view that genetic information should be treated the same as other types of medical information.

> *"Genetic tests should be treated just like any other test." [Non-genetics HP, 6–10 years of experience]*

Training and awareness

An additional issue that arose was a lack of professional training and awareness around the potential insurance implications of genetic testing. No respondents reported attending formal training about this issue (Table 4). Although a minority (n=5/23) attended informal sessions on the subject, 3/5 of those indicated that these sessions did not provide adequate training.

Although all HPs (n=18) who saw adults considering predictive testing reported always discussing insurance implications with those patients, over half of respondents (n=13/22) felt they did not have sufficient knowledge to properly advise clients, and 41% (n=9/22) reported they understood the insurance implications of genetic testing

either *not particularly well* or *not well at all.* Less than 30% (n=6/21) had "good" knowledge (four or five correct answers to knowledge questions) (Table 5 and Appendix 2).

Discussion

To our knowledge, this is the first study to systematically document the views and experiences of New Zealand HPs about the use of genetic test results in insurance underwriting, including its impact on patients and its regulation.

Notably, over half of the surveyed HPs reported patients delaying genetic testing "often or sometimes" because of concerns about insurance discrimination. Concerningly, a number of respondents also reported patients refused testing altogether for this reason. Our findings highlight the urgency of the problem of GD occurring in the New Zealand insurance industry, and suggest that far stronger regulatory protections are required.

More than half of the surveyed HPs also reported patients being denied insurance policies and, in some cases where policies were already in place, denied cover for certain treatments relating to their genetic risk factors. Research in Australia similarly describes direct consumer reports of GD in life insurance, sometimes even when surgery or other preventive measures have virtually removed any disease risk.[22,25] Our findings indicate similar trends in New Zealand—future research in New Zealand should survey consumers to capture their views and experiences directly.

New Zealand HPs expressed a clear preference for increased regulation of the insurance industry. Most HPs agreed that a moratorium, similar to the UK and Australian approach, should be put in place as a temporary measure, but a strong majority also stated that the New Zealand government should introduce legislation to regulate the use of genetic results in insurance underwriting. These findings mirror the larger Australian study,[25] which shows that even after the self-regulated moratorium was introduced in Australia, an overwhelming majority of HPs believed self-regulation by life insurers was insufficient and that government regulation and legislation were required.

All HPs with adult patients considering predictive testing reported always discussing insurance implications with those patients, demonstrating that HPs recognise the importance of addressing this topic during pre-test genetic counselling. Given the role of HPs in obtaining informed consent for genetic testing, the self-identified deficits in HPs' understanding, and lack of training about the potential insurance implications of genetic testing, the current situation is concerning.

New Zealand HPs' limited awareness in this area may be exacerbated by the industry's lack of transparency and reluctance to share any information about their internal policies about use of genetic test results. New Zealand, like Australia, has a Financial Services Council (NZ FSC). While New Zealand FSC guidelines about insurers' use of genetic results were previously published online, they are no longer publicly available. Although the New Zealand FSC provided our research team in 2021 with a copy of the member guideline on genetic testing for *life insurers*, they advised no guidelines existed at the time for *health insurers*. They further advised that there is currently no standard documentation for how genetic testing information is used by the New Zealand life or health insurance industry, prompting concerns regarding how individuals or clinicians can access information about how genetic information may be used. Comments made by HPs in free text similarly raise issues regarding industry transparency and lack of information regarding how genetic test results are used. This further highlights issues with self-regulation that were raised by respondent HPs, and the need for government oversight and regulation to ensure transparency and consumer protection.

One limitation of our study is the small sample size. Given the size of the profession, however, the sample does represent a high proportion of eligible genetics HPs in New Zealand and substantial cumulative years of professional experience (over 240 years). The study also reflects similar results in a larger Australian study.[25] For non-genetics HPs, the sample size substantially limits the generalisability of the findings. Another limitation is that reports of patient experiences are second-hand, which could impact the accuracy of HPs' recollections. Future research should focus on gathering the experiences of New Zealand patients directly.

Our findings demonstrate evidence of New Zealand consumers being deterred from clinical genetic testing because of GD fears, and concerns from HPs about industry self-regulation. New Zealand HPs strongly believe government regulation of GD through national legislation is required. In order for the many benefits of genomic medicine to be realised in New Zealand, far stronger consumer protections against GD occurring in the insurance industry are required. Future research should focus on documenting experiences and views about this issue from the New Zealand public directly.

COMPETING INTERESTS
Nil.

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Appendices

Appendix 1

Demographic information	
Sex	○Male
	○Female
	○Prefer not to say
Profession	○Clinical geneticist
	○Genetics fellow
	○Associate genetic counsellor
	○Certified genetic counsellor
	○Oncologist
	○Genetic pathologist
	○Other
Profession	_____
I have been practising as a [profqualnz] for	○0–5 years
	○6–10 years
	○11–15 years
	○15–20 years
	○more than 20 years
I have been practising as a [profqualnz] for	○0–5 years
	○6–10 years
	○11–15 years
	○15–20 years
	○more than 20 years
I have been practising as a [profothernz] for	○0–5 years
	○6–10 years
	○11–15 years
	○15–20 years
	○more than 20 years
On average, the number of formal appointments I take with patients who are considering genetic testing, by phone or in person, per fortnight, is	○0–5
	○6–10
	○11–20
	○more than 20

Demographic information	
The health service where I primarily work is in the	○Private sector
	○Public sector
	○Both
The health service where I primarily work is	○Urban
	○Regional/rural
I see/speak with patients who are considering testing in the following scenarios [tick all that apply]	□Diagnostic testing in adults
	□Diagnostic testing in children
	□Predictive testing in unaffected adults
	□Predictive testing in unaffected children
	□Carrier testing for recessive conditions in adults
	□Prenatal testing
	□The return of secondary findings from clinical testing
	□The return of secondary findings from research
	□Other
Other	_____

Training and education	
Did you participate in the previous survey on genetics and insurance in 2017?	○Yes
	○No
	○I do not remember
Has your health service provided, or have you attended, any training or information sessions regarding the insurance implications of genetic testing? [select all that apply]	□Yes, formal training
	□Yes, information sessions
	□No
Do you feel this training has been adequate?	○Yes
	○No
How well do you feel you now understand insurance implications for individuals undergoing genetic testing	○Extremely well
	○Reasonably well
	○ Not particularly well
	○ Not well at all
Do you feel you have sufficient knowledge about the current insurance implications of genetic testing to properly advise patients?	○Yes
	○No

How often do you estimate patients delay or refus predictive genetic testing because of life, income or trauma/critical illness insurance concerns?				
	Often	Sometimes	Rarely	Never
Delay	○	○	○	○
Refuse	○	○	○	○

How often do you estimate patients delay or refuse genetic testing because of travel insurance concerns?				
	Often	Sometimes	Rarely	Never
Delay	○	○	○	○
Refuse	○	○	○	○
Are you, or have you been, involved in recruiting participants into research studies?	○Yes			
	○No			
How often do you estimate participants refuse or are concerned about being involved with genetic RESEARCH because of life, income or disability insurance concerns?				
	Often	Sometimes	Rarely	Never
Refuse	○	○	○	○
Concerned	○	○	○	○
Have patient/s told you about having had an adverse insurance outcome on the basis of genetic test results? (for example, having difficulty obtaining a policy, having an increased premium, or having a policy application denied)?	○Yes			
	○No			
Please provide further details (if applicable):	_____			
Does your health service have an agreed policy regarding communicating with patients about insurance that has been discussed with implications of genetic testing?	○Yes, a written policy			
	○Yes – a verbal policy that has been discussed with me or at meetings at which I was present			
	○No			
	○I don't know			

I discuss insurance implications with clients in the following scenarios: (only those which you previously selected will appear here)			
	always	sometimes	never
Diagnostic testing in adults	○	○	○
Diagnostic testing in children	○	○	○
Predictive testing in unaffected adults	○	○	○
Predictive testing in unaffected children	○	○	○
Carrier testing for recessive conditions in adults	○	○	○
Prenatal testing	○	○	○
The return of secondary findings from clinical testing	○	○	○
The return of secondary findings from research	○	○	○
[testtypeothernz]	○	○	○
You indicated that you [predadultnz:checked] discuss insurance implications for predictive testing in adults. Why is this?	_____		

Consent	
When obtaining consent for genetic testing, does your health service have a specific form for predictive testing in adults?	○Yes
	○ No, there is one standard consent form used for all testing
Does the standard consent form include a statement about insurance implications?	○Yes
	○No
Does the form contain a statement about insurance implications?	○Yes
	○No
Further details (if applicable):	_____

Personal views	
We understand that you are a health professional and not a legal or insurance professional. However, we are interested in your personal views on the following matters, based on your experience as a health professional.	
In Australia and New Zealand, life insurance companies are legally allowed to ask for and use genetic test results when underwriting policies, and can refuse cover or increase the cost of premiums on the basis of those results. Do you have concerns regarding this situation in New Zealand?	○Yes ○No
[Optional text]	_____
Are you aware that there was a change in policy on 1 July 2019 in Australia, and a moratorium was introduced on the use of genetic testing in life insurance underwriting in Australia?	○Yes ○No
How did you become aware? [select all that apply]	□Through my health service □Through a news source or social media □Through the HGSA or another professional body □Through the insurance industry directly □Other

The Australian moratorium is a self-regulated (regulated by the insurance industry, not by government) policy change. From 1 July 2019, Australian life insurers have agreed not to ask for or use applicants' genetic test results when underwriting policies worth up to **• $500,000 for life cover,** **• $200,000 for trauma/critical illness cover, and** **• $4000/month for income protection.** **For policies worth over this amount, Australian life insurers will still be able to use genetic test results when underwriting.**	
Based on your professional experience, how do you feel about a moratorium with these terms as a solution to genetic discrimination in life insurance?	○Very satisfied – this is the ideal solution
	○ Somewhat satisfied – this is a pretty good solution
	○Somewhat dissatisfied – the solution could be better
	○Very dissatisfied – the solution should be much better
[Optional text]	_____
In your opinion, how should insurers' compliance with such a moratorium on using genetic test results in life insurance be regulated? [select all that apply]	□Self-regulation by the life insurance industry (FSC) [this is the current situation in Aust]
	□Regulation through legally enforceable rules
	□Other
In the UK, there is a moratorium that involves a formal agreement between the UK government and the Life Insurance Industry. Do you think a formal agreement between the New Zealand government and industry (Financial Services Council) is required on this issue in New Zealand	○Yes
	○No
[optional comment]	_____ (Optional field)
Do you think the New Zealand government should introduce legislation to regulate the use of genetic test results in life insurance?	○Yes
	○No
[optional comment]	_____ (Optional field)

Please answer the following questions to the best of your knowledge. **In New Zealand:**			
	True	False	I don't know
If a patient has an unfavourable genetic test result, their adult child must advise a life insurance company of the parent's genetic results when applying for a new insurance policy	○	○	○
Individuals with a current life insurance policy must notify their existing insurer if they get an unfavourable genetic test result	○	○	○
Life insurance companies are allowed to discriminate based on genetic test results, but health insurance companies are not	○	○	○
If a patient with an unfavourable genetic test result undertakes risk-reducing measures such as surveillance or surgery, an insurer must take this into account when assessing their risk	○	○	○
Travel insuers are also allowed to use genetic test results when underwriting policies	○	○	○

Final comments	
In your opinion, what, if any, would be the benefits of a moratorium on genetic testing and life insurance in New Zealand? [optional]	_____ (Optional field)
In your opinion, what, if any, would be the limitations of such a moratorium in New Zealand? [optional]	_____ (Optional field)
Do you have any final comments about this issue? [optional]	_____ (Optional field)

Further contact	
As part of this research project, we may want to contact you to discuss the matters raised in this survey further. Any data collected in this follow-up interview will be de-identified before being published or shared. If you consent to being contacted for a follow-up interview, please provide your contact details below.	○I prefer to remain anonymous ○I am happy to be contacted in the future
Name	_____
Email address	_____
Best telephone contact number	_____

Appendix 2

Knowledge questions					
Question (Genetics HPs n=15; non-genetics HPs n=6)	**True/ false (correct answer)**	**Group (n=21)**	**Correct answer**	**Incorrect answer**	**Unsure**
If a patient has an unfavourable genetic test result, their adult child must advise a life insurance company of the parent's genetic results when applying for a new insurance policy.	False	Total	13/21 (62)	6/21 (29)	2/21 (10)
		Genetics HPs	10/15 (67)	4/15 (27)	1/15 (7)
		Non-genetics HPs	3/6 (50)	2/6 (33)	1/6 (17)
Individuals with a current life insurance policy must notify their existing insurer if they get an unfavourable genetic test result.	False	Total	15/21 (71)	5/21 (24)	1/21 (5)
		Genetics HPs	13/15 (87)	2/15 (13)	0/15 (0)
		Non-genetics HPs	2/6 (33)	3/6 (50)	1/6 (17)
Life insurance companies are allowed to discriminate based on genetic test results, but health insurance companies are not.	False	Total	15/21 (71)	0/21 (0)	6/21 (29)
		Genetics HPs	12/15 (80)	0/15 (0)	3/15 (20)
		Non-genetics HPs	3/6 (50)	0/6 (0)	3/6 (50)
Travel insurers are also allowed to use genetic test results when underwriting policies.	True	Total	9/21 (43)	3/21 (14)	9/21 (43)
		Genetics HPs	7/15 (47)	1/15 (7)	7/15 (47)
		Non-genetics HPs	2/6 (33)	2/6 (33)	2/6 (33)
If a patient with an unfavourable genetic test result undertakes risk-reducing measures such as surveillance or surgery, an insurer must take this into account when assessing their risk	True	Total	8/21 (38)	6/21 (29)	7/21 (33)
		Genetics HPs	6/15 (40)	5/15 (33)	4/15 (27)
		Non-genetics HPs	2/6 (33)	1/6 (17)	3/6 (50)

A review of trauma laparotomy at Christchurch Hospital

Tengo Kandelaki, Melissa Evans, Christopher J Wakeman, Andrew McCombie

ABSTRACT

AIM: Trauma is one of the leading causes for years of life lost in New Zealand. Its costs to acute care services alone amount to hundreds of millions per year, and it is the main contributor to years of life lost in patients under 40. Since 2016, the Canterbury Trauma Registry has been actively collecting data on all major traumas presenting to Christchurch hospital. This study will aim to define the demographics of trauma laparotomy patients presenting to Christchurch Hospital, and to assess the relationship between missed injuries (MI) on computed tomography (CT) imaging and time to theatre.

METHODS: A retrospective study of trauma patient from June 2016 to February 2019. Data for major trauma patients were supplied from the Canterbury Trauma Registry. Data for minor trauma patients were individually selected from the online operative procedures registry. Non-parametric analysis was undertaken with an independent sample Kruskal–Wallis test alongside pairwise comparisons.

RESULTS: Sixty trauma laparotomies were performed over 36 months, predominantly male gender (43/60) and under 40 years of age (39/60). Motor vehicle accident (31/60) and knife injuries (10/60) were the most common mechanisms. Fourty-three out of sixty patients received pre-operative CT scans. Fourty out of sixty patients received a CT scan within 2 hours. Large bowel injuries (four cases) and small bowel (three cases) were the most common missed injuries on pre-operative CT. Small bowel injuries are the predominate injury in blunt trauma while diaphragm and liver injuries predominated in penetrating trauma. Four patients did not undergo laparotomy within 24 hours. There is a statistically significant difference ($p<0.001$) in time to operating theatre between patients with no pre-operative CT and patients with no MI on CT and patients with MI on CT. There is no statistically significant difference ($p<0.231$) in time to operating theatre in patients with no MI on CT and patients with MI on CT.

CONCLUSION: There is no statistically significant difference in time to operation between trauma laparotomy patients with no MI on pre-operative CT to patients with MI on pre-operative CT. There are recognisable injury patterns in trauma patients. There are delays in trauma patients receiving prompt CT imaging. CT imaging can miss life-threatening injury, close patient observation and further examination, and imaging or operative therapy may be required even if initial imaging is reassuring.

Trauma is one of the leading causes for years of life lost in New Zealand and disproportionately affects younger age groups.[1] In 2021, Accident Compensation Corporation's (ACC) annual public health acute services costs alone were $578 million NZD, with total expenditure of key claims totalling $8.7 billion.[2] The main contributing group to the total lifetime cost of injury is patients under the age of 40.

New Zealand centres have improved mortality through advancements in damage control operations, supportive care and endovascular therapies. Continued evaluation of trauma systems against a selection of quality indicators (QIs) provides opportunity for improvement in clinical practice and guidelines, patient mortality and morbidity, and appropriate resource allocation and financing.[3] Time to laparotomy, time to computed tomography (CT) scan and missed injuries (MI) are common indicators for evaluating the performance of trauma systems.[4,5,6] However, the independent relationship of these QIs with mortality and their downstream effects on additional performance indicator remains less certain.[7,8,9]

Since the beginning of 2016, the Christchurch Hospital trauma service has compiled a database of all major trauma admissions to Christchurch Hospital to assess the processes and outcomes of trauma care in Christchurch. Despite this wealth of available information there have been relatively few attempts at meaningful interpretation of the available data. The aims of this study are to describe the demographics of trauma laparotomy patients that have presented to Christchurch Hospital, and to assess the relationship between MI on CT imaging and time to laparotomy.

Method

The chosen variables included basic patient demographic data, quality indicators derived from the American College of Surgeons Committee on Trauma (ACS-COT), CT report findings, operative findings and common complications

following emergency abdominal surgery.

Data sourced from the Christchurch major trauma database were used to identify patient details for major trauma laparotomies. This database only includes trauma with and an injury severity score (ISS) of 13 or above. The details for trauma laparotomies with an ISS below 13 were sourced through a query for "laparotomy" in the digital operative note publishing system (scOPe). These results were then manually filtered and cross checked for the relevant trauma laparotomy cases. Non-major traumas (ISS less than 13) that underwent trauma laparotomy were selected during the interrogation of operative notes and added to the final dataset. Trauma laparotomies between the dates of July 2016 and July 2019 were included in the study.

The data for CT scan reports, admission time to the Emergency Department (ED), operative findings, operative procedures, transfusion, infection, stoma and dehiscence was gathered from online notes, ED and inpatient discharge summaries, outpatient letters, outpatient referrals, formal CT reports and entries in the trauma database. Post-operative complications were limited to the first 30 days post-op. The data for time to CT scan were gathered directly from the local digital imaging review platform (Inteleviewer).

To determine if there was a difference in CT scan reports and operative finding, there was a comparison between the finalised report and the listed operative findings on the digital operation note. A clinical judgement was made on which non-reported injuries were significant enough to count as an MI. Allowances were made for small areas of fluid collection, oedema, and small tears without perforation, etc. Injury with hollow viscus perforation (of any size) which was not included on the CT report was included as a missed finding.

Infection was restricted to the general surgery field of operation. In the cases of diaphragm repair this included the pleural cavity (not lungs i.e., excluding pneumonia). The diagnosis of infection required a combination of clinical, microbiological and radiological evidence. The infection must have been treated with an appropriate course of targeted antibiotics therapy. Prophylactic peri-operative antibiotics and empiric antibiotics that were stopped within 24 hours were not included. Any suspected infective condition requiring surgical debridement was included.

In the instances where the same procedure was done multiple times in a simple laparotomy (e.g., small bowel repairs, liver laceration repairs) these were recorded as individual procedures. Every separately classified procedure performed in the same laparotomy was recorded.

Statistical packages for social sciences (SPSS) version 28 was used for statistical analysis. The distribution of time to laparotomy was not normally distributed and the groups numbered less than 30. Therefore, non-parametric analysis was undertaken with an Independent-Samples Kruskal–Wallis Test alongside pairwise comparisons.[10]

Results

There were 1,237 major trauma patients admitted between July 2016 and July 2019. Fifty-six trauma laparotomies were performed, with an additional four laparotomies for non-major traumas. There was a male predominance (43/60) over female (17/60) (χ^2=11.267; p<0.001). Motor vehicle crash (MVC) (31/60) and knife injuries (10/60) were the predominant mechanism. Forty-three patients received pre-operating CT imaging, while 17 proceeded directly to theatre (see Figure 1). In ten patients, operative findings discovered injuries which were missed by initial CT imaging. These included four large bowel injuries, three small bowel perforations, one ischaemic bowel requiring resection, one mesenteric haematoma, one ureteric injury and one bladder injury. There were ten planned re-looks and six unplanned relooks, five stoma formations, three post-operative infections, one fascial dehiscence, and 40 patients who required transfusion (see Figure 2). The most common types of operative procedures were small bowel resection/repair (23 performed) and large bowel resection/repair with or without stoma formation (17 performed). All four non-major trauma patients had penetrating injuries, the subsequent procedures were two exploratory laparotomies, one diaphragm repair, one large bowel repair and one post-operative gonadal artery embolisation. There were three mortalities, these cases were all within the no pre-operative CT group. Two occurring within 24 hours secondary to complications of haemorrhagic shock, and one at 72 hours secondary to neurotrauma. In three-way comparisons there was a statistically significant difference (p<0.001) in the median time to laparotomy (hours) between the no CT (1.05), no missed injury on CT (4.45) and missed injury on CT (12.025) groups. Pairwise comparisons demonstrated statistically significant differences between the no CT vs no MI on CT (p<0.001), and the no CT vs MI on CT groups (p<0.001). There was no statistically significant difference between the no MI on CT and MI on CT groups (p=0.231).

Table 1: Patient demographics.

Gender	
Male	43 (72%)
Female	17 (28%)
Age	
0–9	1 (1.7%)
10–19	7 (11.7%)
20–29	15 (25%)
30–39	16 (26.7%)
40–49	11 (18.3%)
50–59	8 (13.3%)
60–69	2 (3.3%)
70+	0 (0%)
ISS	
<13	4 (6.7%)
13–19	16 (26.7%)
20–29	21 (35%)
30–39	11 (18.3%)
40+	8 (13.3%)
Median	24
Upper Quartile	34
Lower Quartile	17
Type	
Blunt	38 (63.3%)
Penetrating	22 (36.7%)
Mechanism	
MVC	31 (51.7%)
Knife	10 (16.7%)
Gunshot	9 (15%)
Fall	3 (5%)
Assault†	1 (1.7%)
Motorbike	1 (1.7%)
Car vs bike	1 (1.7%)

Table 1 (continued): Patient demographics.

Mechanism (continued)	
Horse	1 (1.7%)
Crane accident	1 (1.7%)
Forestry	1 (1.7%)
Skiing	1 (1.7%)
Time to CT (hours)	
<1	14 (23.3%)
1–2	26 (43.3%)
>2	3 (5%)
N/A	17 (28.3%)
Time to laparotomy (hours)	
<1	9 (15%)
1–2	12 (20%)
>2–6	25 (41.7%)
>6–24	10 (16.7%)
>24	4 (6.7%)

†Excludes knife and gunshot mechanisms

Table 2: Time to laparotomy stratified by MI on CT.

Group	**Number**	**Gender (M/F)**	**Median age (years) and IQR**	**Mean ISS**	**Median time to laparotomy (hours)**
No CT	17	12/5	35	35.65	1.05
No MI on CT	33	23/10	35	24.67	4.45
MI on CT	10	8/2	31	22	12.025

Figure 1: Correlation of CT reports with operative findings.

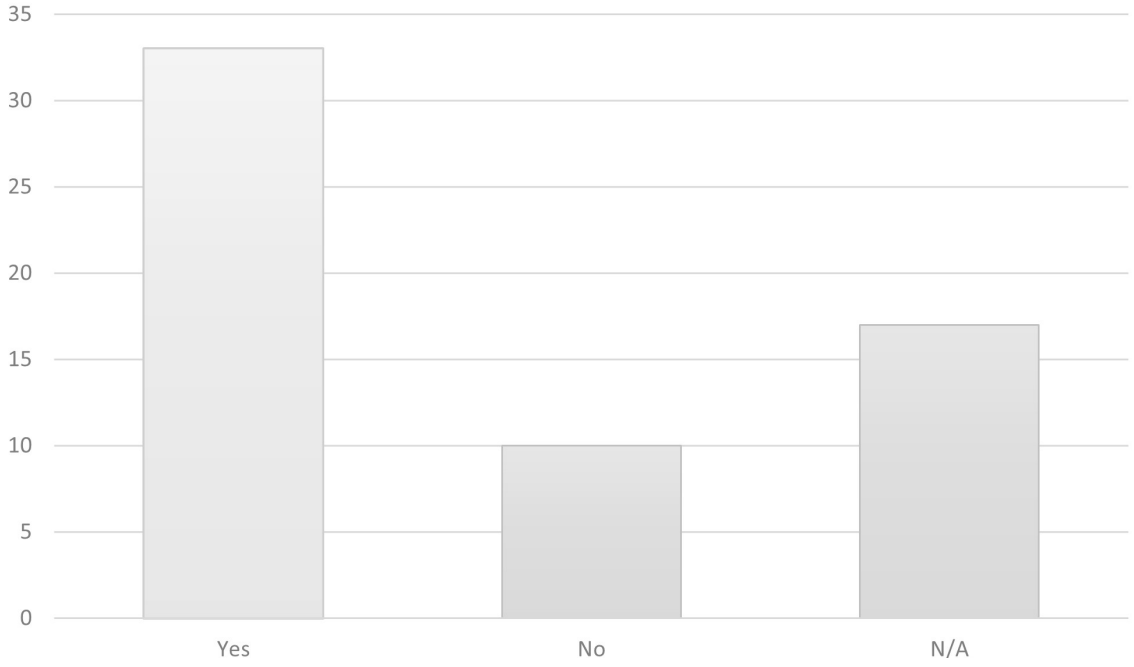


Figure 2: Additional procedures and complications.

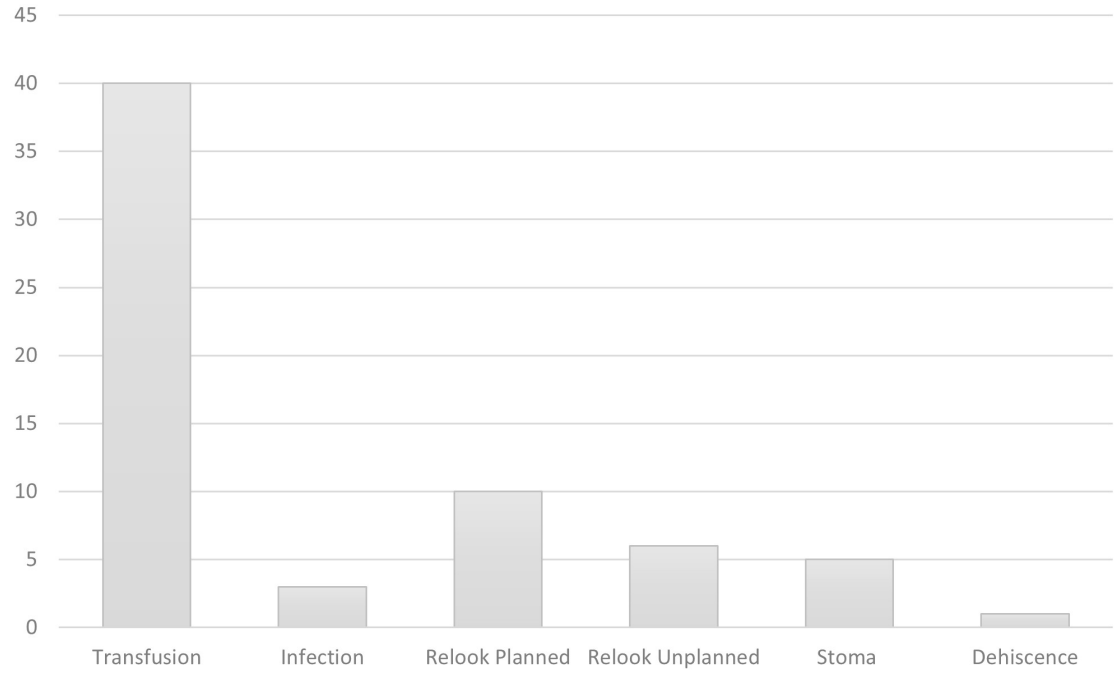


Table 3: Operative procedure stratified by operative time.

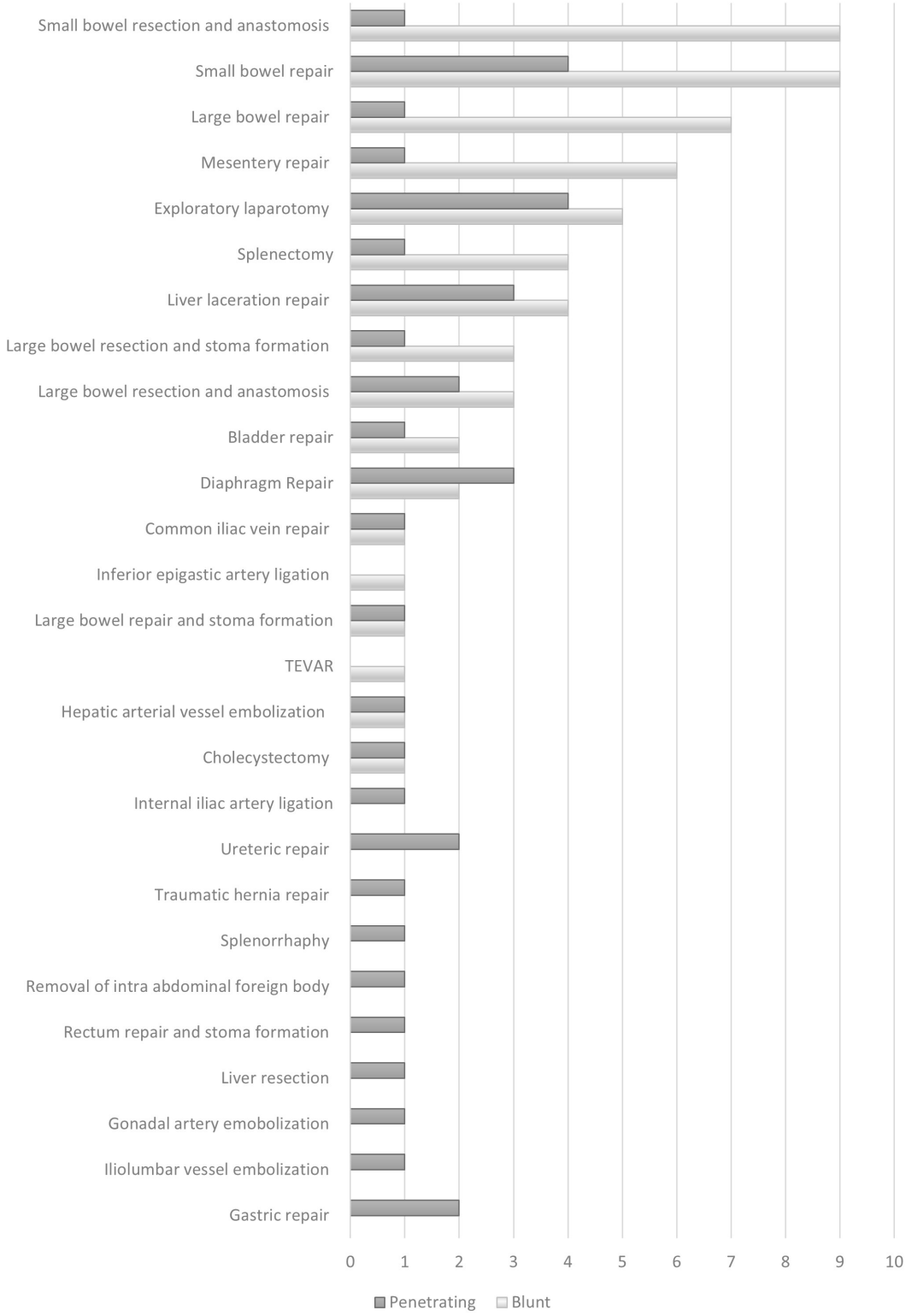
Procedures	Time to operating theatre (hours)										
	1	2	3	4	5	6	6–12	12–24	24–48	48–72	72+*
Gastric repair	1 (4.5%)	1 (4.2%)	0	0	0	0	0	0	0	0	0
Cholecystectomy	1 (4.5%)	0	0	0	0	0	0	0	0	1 (50%)	0
Diaphragm repair	0	1 (4.2%)	1 (9.1%)	1 (12.5%)	0	1 (11.1%)	0	0	1 (100%)	0	0
Exploratory laparotomy	1 (4.5%)	4 (16.6%)	1 (9.1%)	1 (12.5%)	0	0	2 (22.2%)	0	0	0	0
IR procedure post OT**	3 (14%)	1 (4.2%)	0	0	0	0	1 (11.1%)	0	0	0	0
Large bowel repair	0	1 (4.2%)	1 (9.1%)	0	2 (25%)	2 (22.2%)	2 (22.2%)	0	0	0	0
Large bowel repair and stoma formation	0	0	1 (9.1%)	0	0	0	0	0	0	0	0
Large bowel resection and anastomosis	1 (4.5%)	2 (8.3%)	0	1 (12.5%)	0	1 (11.1%)	1 (11.1%)	0	0	0	0
Large bowel resection and stoma formation	0	2 (8.3%)	0	1 (12.5%)	0	1 (11.1%)	0	0	0	0	1 (50%)
Liver laceration repair	1 (4.5%)	2 (8.3%)	2 (18.2%)	1 (12.5%)	0	0	0	0	0	1 (50%)	0
Liver resection	1 (4.5%)	0	0	0	0	0	0	0	0	0	0
Mesentery repair	1 (4.5%)	3 (12.5%)	1 (9.1%)	0	1 (12.5%)	1 (11.1%)	1 (11.1%)	0	0	0	0
Rectum repair and stoma formation	0	0	0	0	0	0	1 (11.1%)	0	0	0	0
Removal of intra-abdominal foreign body	0	0	0	0	1 (12.5%)	0	0	0	0	0	0
Small bowel repair	2 (9%)	2 (8.3%)	2 (18.2%)	2 (25%)	1 (12.5%)	1 (11.1%)	1 (11.1%)	1 (33%)	0	0	1 (50%)
Small bowel resection and anastomosis	2 (9%)	1 (4.2%)	1 (9.1%)	1 (12.5%)	1 (12.5%)	2 (22.2%)	0	1 (33%)	0	0	0

Table 3 (continued): Operative procedure stratified by operative time.

Procedures	Time to operating theatre (hours)										
	1	2	3	4	5	6	6–12	12–24	24–48	48–72	72+*
Splenectomy	2 (9%)	1 (4.2%)	1 (9.1%)	0	1 (12.5%)	0	0	0	0	0	0
Splenorrhaphy	1 (4.5%)	0	0	0	0	0	0	0	0	0	0
Traumatic hernia repair	0	1 (4.2%)	0	0	0	0	0	0	0	0	0
Urological procedure †	2 (9.1%)	2 (8.3%)	0	0	0	0	0	1 (33%)	0	0	0
Vascular procedure ††	3 (14%)	0	0	0	1 (12.5%)	0	0	0	0	0	0

* Small bowel repair performed at day 5. Large bowel resection and stoma formation performed at day 7.
** Post-operative IR procedures included TEVAR, hepatic arterial vessel embolisation, iliolumbar vessel embolisation and gonadal artery embolisation.
† Urology procedures included bladder repair and ureteric repair.
†† Vascular surgery procedures included internal iliac artery ligation, common iliac vein repair and inferior epigastric artery ligation.

Figure 3: Operative procedures stratified by trauma.



Discussion

In the 60 trauma laparotomies performed, there was a statistically significant difference between the median times to operating theatre between the direct to operating theatre cohort and the no MI on CT and MI on CT cohorts. There was no statistically significant difference in the time to operating theatre or mortality between the MI on CT and no MI on CT cohorts. These findings suggest that missed injuries on CT imaging in abdominal trauma patients requiring a laparotomy does not correlate to a statistically significant delay to theatre or worse mortality outcomes compared to patients who do not have missed injuries on CT imaging.

The baseline demographics of male to female ratio, age and mechanism are similar to other studies in developed countries.[11,12] The male predominance is also consistent with the general major trauma cohort over the study period (male patients constituted 72% of general major trauma patients). There are clear patterns of injury with blunt and penetrating trauma, with hollow viscus repair/resection predominating in blunt trauma while diaphragm and hepatic repair predominate in penetrating trauma. The 56 patients who underwent trauma laparotomy represent 4.5% of the total major trauma cohort. This is similar to previous studies, a 2017 multicentre study of 74,048 major trauma patients in the United States (US) reported a trauma laparotomy rate of 4%, an analysis of the Victorian State Trauma Registry in 2019 calculated a trauma laparotomy rate of 4.1%. These studies reported mortalities in the trauma laparotomy cohort of 21% and 10.9% respectively,[11,13] a 2021 study of trauma patients with hollow viscus injury in northern New Zealand reported a mortality rate of 5%,[14] the mortality rate in this study was also 5%. The variance in mortality rates could be attributable to patient selection for operative intervention, method for mortality reporting (US study excluded patients not classified as emergent laparotomies in mortality calculations), difference in ISS and other patient demographics, different injury mechanisms and improvements in trauma systems over time (data collection periods in the US and Australian studies were from 2012–2013 and 2007–2016).

Interestingly, there were more exploratory laparotomies in the blunt trauma compared to the penetrating trauma groups. Higher rates of negative/exploratory laparotomy are typically reported in penetrating trauma patients.[15]

Time to CT is a performance indicator for evaluating in hospital trauma care, early CT scan imaging of appropriate trauma patients has been associated with decreased mortality.[16] Forty out of 60 received a CT scan within 2 hours of arrival, 17 patients proceeded to theatre without prior CT imaging. Several factor could influence time to CT in a trauma setting including if a trauma call was activated, overnight admission, number of patients requiring CT scans and staffing resources. The three other New Zealand trauma networks (Northern, Midlands and Central) reported that 78%, 78% and 65% of major trauma patients overall received diagnostic imaging within 2 hours.[17] However, the time to CT specifically for trauma laparotomy patients and the proportion that proceed directly to operating theatre had not been specifically described.

Missed injuries on CT scan were hollow viscus injuries requiring resection/repair and mesenteric injuries. Blunt bowel and mesenteric injuries remain challenging to identify on index CT scan as there is a lack of specific imaging findings which can conclusively confirm or exclude its presence. Often, indirect evidence is gathered to produce a picture of risk for an occult/suspected injury; however, there is limited research investigating the positive and negative predictive values of these indirect findings in major trauma or the future consequences of missed injuries.[18] The patterns of missed injuries are similar to other studies in the literature.[19] There was no statistically significant difference demonstrated in time to operating theatre between the MI on CT and no MI on CT groups. There were no cases of mortality recorded in these groups, with all three mortalities recorded in the direct to operating theatre cohort. In this study, 17 laparotomies proceeded directly to theatre due to haemodynamic instability and positive findings on other imaging modalities. Previous studies have demonstrated similar results, Loftus et al. found no statistical difference in mortality or time to operative intervention in the CT missed bowel injury and no missed bowel injury groups.[20] Kommunuri et al. found no difference in mortality or morbidity in patients with delayed diagnosis of hollow viscus injury compared to those without delayed diagnosis, the two deaths in their study cohort (secondary to neurotrauma) also occurred in patients taken directly to the operating theatre without preoperative imaging.[14] The relationship between delayed operation and mortality is uncertain for abdominal trauma patients overall. Certain studies demonstrate that time to operating the-

atre improved survival in the haemodynamically unstable patient; however, this association diminished when evaluating the entire major trauma cohort.[5,9,21] Alternatively, there is conflicting evidence that performing CT scans in haemodynamically unstable major trauma patients can reduce the need for operative intervention and improve survival.[22,23] There is likely a stratified benefit with certain injury patterns deriving the most benefit in expedient operative intervention; however, these can be difficult to identify prior to obtaining cross sectional imaging with the resources and imaging modalities conventionally available during the primary survey.

Whilst it cannot be delineated if the transfusion requirements in this group of patients were due to abdominal injuries or associated injuries, 40 from 60 patients received blood products in this group. Pre-hospital haemorrhage management is an independent risk factor for mortality[24,25] and a potentially under explored area for potential improvement. Currently, there is no capacity for ambulance staff to deliver blood products prior to arrival to the ED, hypotensive trauma patients may be receiving excessive volumes of crystalloid fluids in the pre-hospital phase. There are known deleterious effects of excessive crystalloid fluid resuscitation in trauma patients,[26] and current Advanced Trauma Life Support guidelines recommend no more than 1.5L of crystalloid prior to commencing blood products.[27]

Prior to this study, there was no formal recording of trauma laparotomy cases at Christchurch Hospital. Anecdotally, the number of cases was thought to be small as the individual surgeon exposure was low. However, this preconception is challenged by this study which demonstrates a rate of trauma laparotomy approximately once every two weeks. There were 21 surgeons who performed the trauma laparotomies over the study timeframe (multiple surgeons in the same operation were counted individually). The range in trauma laparotomies performed by this cohort of surgeons was between 1 and 9 laparotomies (median 3). The appointment of a surgeon with a subspecialty in trauma could be considered given this new insight into trauma laparotomies, as well as the availability of a combined Interventional Radiology operating suite for these trauma cases.

Conclusion

There were 60 trauma laparotomies performed at Christchurch Hospital over a period of 3 years, most patients were under 40 years old with a predominance of male gender. The majority of trauma laparotomies were due to MVC and knife injuries with small bowel and large bowel injuries the most common injury pattern. The majority of patients received pre-operative CT scanning as part of the trauma work up; however, 17 patients proceeded directly to theatre on the basis of clinical signs or other imaging modalities. Missed injuries on CT were mainly hollow viscus small bowel and large bowel injuries. There was no statistically significant difference in pairwise comparisons in the time to laparotomy between the MI on CT and no MI on CT groups. Statistically significant changes are demonstrated when comparing the no pre-operative CT group in both three-way and pairwise comparisons. There was no difference in mortality between the MI on CT and no MI on CT groups.

Limitations and areas for further research

This was a study describing the characteristics of one cohort of patients. As there was no comparison or control group no rate or risk calculation can be performed. There are limited conclusions that can be drawn regarding the relationship between the measured parameters and recorded outcomes. Relatively low patient numbers could result in this study being underpowered to identify a true association in the measured variables. Despite the entry of patient details into a dedicated database, retrospective studies are at risk of selection, recall and measurement biases, as well as the inability to control for unknown confounders. A retrospective comparison study would be a start towards identifying risk factors and quality indicators which are important for patient outcomes. Once these are identified a prospective study could give more robust research into management changes that can influence outcomes. Specific groups that require more detail include pre-laparotomy/pre-hospital mortality patients and major trauma patients that were treated conservatively.

There are currently no data on the Trauma Registry that identify complications of trauma laparotomy. These could be a useful measure to track if there is a robust method for data collection and enough staff resources available. Alternatively, prospective studies could follow a cohort of representative patients to determine the complication rate. The UK has a national emergency laparotomy database which is annually analysed. A similar collaborative project across district health boards would help the problem of relatively small numbers of trauma laparotomies occurring at each centre.

COMPETING INTERESTS
Nil.

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Food security during nuclear winter: a preliminary agricultural sector analysis for Aotearoa New Zealand

Nick Wilson, Marnie Prickett, Matt Boyd

ABSTRACT

AIM: We aimed to estimate the current dietary energy content of food exports for Aotearoa New Zealand and food security during "nuclear winter" scenarios following a nuclear war.

METHODS: From published sources we estimated dietary energy available from the major domains of food exports, with adjustments for wastage. The impacts on food production in New Zealand during three nuclear winter scenarios were based on those published in Nature Food in 2022 and from an earlier New Zealand Planning Council study.

RESULTS: Current major food exports are equivalent to 3.9 times current dietary energy intakes for all New Zealand citizens i.e., 34,100 kJ (8150 kcal) per person per day. Exported dairy products were estimated to be able to provide 338% of this energy intake, followed by exports of meat (34%), fruit (8.6%), alcohol (4.8%), marine products (4.6%) and vegetables (2.7%). During the various nuclear winter scenarios considered (minimal to severe), food production available from diverted exported foods was estimated to still be 3.6 to 1.5 times current daily energy intakes. Nevertheless, the agriculture sector could be at risk of various levels of collapse from lack of imports (e.g., diesel, fertiliser, pesticides, seeds, and machinery parts) and from socio-economic collapse, including if the financial system collapsed.

CONCLUSIONS: This analysis suggests that this country could theoretically have excess food production capacity, even after a severe nuclear winter scenario. But this benefit could be very short-term if the agricultural system was not made more resilient to potential lack of international trade and socio-economic collapse in a post-catastrophe setting.

The survival of human civilisation, or its continued flourishing, could be threatened by a global catastrophe abruptly reducing sunlight reaching the earth.[1,2] Such scenarios could include nuclear winter arising from a nuclear war,[3] large volcanic eruptions,[4,5] and a large asteroid/comet impact.[6] Resulting global climate impacts could include a drop in mean temperature that would limit food production possibly causing a catastrophic global food shock.[1] Modelling studies indicate that the impacts of such catastrophes are likely to be highly heterogeneous around the world.[3,7] It is sometimes thought, for example, that islands in the Southern Hemisphere might do better than countries in Northern Hemisphere landmasses during nuclear winter,[8,9] and similarly for islands after volcanic winter.[10]

Collectively these threats are not improbable. Estimates for the annual probability of inadvertent nuclear war include 1%,[11] or in the 0.3% to 3% range for all kinds of nuclear war.[12] However, the uncertainty may even be higher and could be increasing with the Russian invasion of Ukraine in 2022.[13] Another consideration is the risk of major volcanic eruptions on the scale of the Indonesian volcano Tambora in 1815. This eruption cooled global climate and contributed to famines in parts of Europe, India and China.[14] Eruptions of a scale of Tambora or greater occur around 1.6 times per millennium,[15] equivalent to around a one in six chance per century.[5] But some estimates put the overall likelihood of a catastrophic global food shock (of >10% loss of production) at 80% this century.[16]

Other catastrophic scenarios include severe pandemics (such as those arising from engineered bioweapons), or global industry-disabling scenarios such as coronal mass ejections or electromagnetic pulses,[17] that might collapse the global economy and isolate remote nations like Aotearoa New Zealand.

Greater efforts are needed to prevent and mitigate all these threats to humanity, but it is also prudent to consider what happens if prevention fails for nations and the international community to plan effectively. In terms of catastrophic pandemics, past work has suggested that isolated island refuges could have a role in ensuring human survival. New Zealand appears relatively well placed in terms of survivability compared to other island nations, with it ranked first in one

study[18] and only behind Australia in others.[19,20] Self-sufficiency on dimensions including food supply would have to be assured, although the previous work also reported the large per person food production capacity of New Zealand.[19,20]

Past work for New Zealand on the impact of nuclear war is substantively out of date as it was done in the 1980s e.g., by the Commission for the Future,[21] the New Zealand Planning Council[22–26] and others.[27] Since this time, New Zealand society has changed in many ways, including the expansion of agricultural production, the growth in food exports, population growth, and technological developments. The scientific understanding of the impacts of abrupt sunlight reduction catastrophes has evolved as well.[28–31]

Given the above, we aimed to begin to explore the food security issues for New Zealand after such catastrophes by describing the current food export economy, as well as the potential food supply when accounting for the climate impacts of a nuclear winter. In this preliminary work, we focused on the food *export* sector, as the data appeared to provide a much clearer picture of food production than the far more diverse and complex domestic food production sector.

Methods

Business-as-usual dietary energy intake of New Zealanders

Adult[32] and child[33] nutrition survey data for New Zealand were used to estimate dietary energy intakes for these population groups by sex. These estimates were then multiplied by the relevant estimated New Zealand population sizes for the fourth quarter of 2021[34] to estimate the national dietary energy intake.

Food export analyses

Food export weights were obtained from the New Zealand Harmonised System for export data[35–37] and 5-year annual averages were calculated for the 5-year period ending June 2020. For reasons of methodological parsimony, we ignored food export categories that were under a 10,000 tonnes annual average in volume.

Food wastage adjustments

The adjustments for potential food wastage are shown in Table 1. These used data from the United States, United Kingdom and Europe. Although work on waste has been conducted in New Zealand,[38] this has not identified waste as a proportion of specific food products taken into the household.

Dietary energy data

For the food exports that were available for intake at the household level after unavoidable wastage (inedible components) and avoidable wastage, we calculated the food energy available. This was done by matching typical foods within each food export category using the New Zealand Food Composition Database.[44] We used representative foods within each category e.g., in the cheese category: "cheddar cheese, code F1015"; and for the apple category: "Royal Gala, code L1150". A full list of codes and the Excel spreadsheet is available on request to the authors.

Nuclear winter scenarios

There is much uncertainty concerning the global impacts of nuclear war and if "nuclear winter" impacts would even occur. Nevertheless, to inform potential planning purposes we considered the three scenarios outlined in Table 2. The key driver of climatic impacts in these scenarios is stratospheric soot injection following nuclear weapon explosions on targets in the Northern Hemisphere. This stratospheric soot results in global cooling which impedes food crop production. In all these scenarios we assumed an effective end to New Zealand's food trade with other countries (including Australia) for both exports and imports. This was also the approach taken in previous New Zealand research.[45]

Results

Business-as-usual dietary energy intake of the New Zealand population

The estimated dietary energy intake of the entire New Zealand population was estimated at 44.4 billion kJ per day (8,686kJ per person per day; Table 3).

Food energy availability from diverted exports

The estimates for the major food exports are detailed in Table 4 and summarised in Table 5. After food wastage adjustments, dairy products were estimated to provide 338% of all the current dietary energy, followed by meat (34%), fruit (8.6%), alcohol (4.8%), marine products (4.6%) and vegetables (2.7%). Overall, these exports were estimated to provide 3.9 times dietary energy intakes for the whole New Zealand population (or 34,098kJ per person per day).

Table 1: Assumptions around inedible fractions of foods and typical avoidable food wastage (for food previously prepared for export which was then assumed to be diverted to the domestic market after a global catastrophe).

Major food export group (if over 10,000 tonnes per year)	Estimated food wastage during transport from food production facility to retailers and then to households [A] *	Estimated inedible fraction of exported food weights (unavoidable waste) [B]	Estimated avoidable wastage for foods entering the household [C]
Dairy products	1%	0%	8% (WRAP)
Marine food products	1%	0% (most exports assumed to be filleted)	8.5% (mid-point of two estimates: 6% (NRDC) and 11% (WRAP))
Alcohol	1%	0%	8% (value for all types of drinks) (WRAP)
Red meat products			
Beef and veal	1%	18% (bone) **	8.5% (mid-point of 6% (NRDC) and 11% (WRAP))
Lamb and mutton	1%	16% (bone) ***	
Fruit			
Apples	5%	12% #	14% (mid-point of 10%[39] and 18% (WRAP) for fruit as a grouping)
Avocados	8%	26% #	
Kiwifruit	6%	18% #	
Fresh vegetables			
Onions (dry)	6%	11% #	16.5% (mid-point of 13%[39] and 20% (WRAP) for fresh vegetables as a grouping)
Potatoes (actually a mix of fresh & frozen)	7%	16% #	
Processed vegetables			
Peas (frozen)	1%	0%	14% for processed vegetables (WRAP)
Sweetcorn (frozen)	1%	0%	

Notes: * Retail waste was estimated from wastage in a US study by the National Resources Defence Council (NRDC)[40] (Table 62 in this NRDC publication). This indicated that the weight of food waste at the levels of "food wholesalers and distributors" and "grocers and markets" was 20% that of the weight of waste at the residential level (we combined the amounts for the three cities in the study). We applied this value to the fresh fruit and vegetable categories (i.e., multiplying the 20% with the summed values in columns [B] and [C]). For processed foods we could not identify specific values but assumed it would be much less than for fresh produce. So, we used a "guesstimate" of 1% to account for some small proportional loss due to expired "use-by-dates", accidental damage and refrigeration failures.

** Given the dominance of carcass meat exports, we ignored boneless meat exports and just used a value for the proportion of bone in a study of New Zealand beef (hind quarter, "commercial composition") at 18% (Table 2 in Bass et al[41]). Of note, is that food can be extracted from bones (e.g., to make soup) so that in disaster circumstances these are a potential food source.

*** Given the dominance of carcass meat exports, we ignored boneless meat exports and just used a value for lamb carcasses of 16%.[42]

Inedible fractions from an average of three European studies as per De Laurentiis et al.[39] Avoidable food waste in the household for the European Union was 5kg/person/year out of 52kg of fruit taken into the household (10%). For vegetables the equivalent value was 13% (9/71). Some of these values are probably conservative e.g., the 16% value is for fresh potatoes, and would be lower for the processed frozen potatoes that are a component of New Zealand's exports.

NRDC: National Resources Defence Council, US wastage data.[40]

WRAP: Data for the United Kingdom (Table 51 in this Report[43]).

Table 2: Three nuclear war and nuclear winter scenarios considered in this study.

Nuclear war scenario	Scale of impact of a nuclear winter	Estimated impact on agricultural production in New Zealand
A war between India and Pakistan	We used the lower end impact (5 teragrams [Tg]) of the estimated 5–47Tg range of stratospheric loading of soot. This is from a major modelling study published in the journal Nature Food in 2022 by Xia et al.[30]	An 8% reduction in major food crops and marine fish*[30]
A war between NATO and the then Warsaw Pact	We used the impacts from a NZ Planning Council study of a 5,000–6,000 megatonne war in July (Northern Hemisphere summer).[45] This was assumed to result in a spring temperature reduction in New Zealand of 3°C, a 2°C reduction in summer and a 1°C reduction for another 18 months.	A 28% reduction (mid-point in the estimated 19–36% reduction in pasture growth in year 1)**[25]
A war between Russia and the United States and its allies	We used the highest value (150Tg) of stratospheric loading of soot used in the work by Xia et al.[30]	A 61% reduction in major food crops and marine fish*[30]

Notes: * This study estimated food energy production for New Zealand as part of a global analysis using data for major food crops (maize, rice, soybean and spring wheat) and marine fish averaged in year 2. For modelling parsimony, we used these specific reductions for across-the-board food production, even though grass growth for livestock production may be less impacted than crop production. This -8% value from Xia et al 5Tg scenario compares with -12% for maize and wheat in year 4 (and a -5% average for years 1–5) in an earlier study (i.e., Jägermeyr et al.: Table S3).[28]
** This New Zealand work[25] estimated pasture dry matter production impacts from nuclear war for Waikato, Canterbury and Southland regions with reductions in year 1 ranging from 19%–36%. For year 2, the range was reductions from 11%–17%. It has also been estimated for New Zealand that a 3°C decline in temperature would delay the maturity of wheat crops in Canterbury by about 40 days.[26] This would probably not be a problem but a 20% decline in solar radiation would result in a probable decline in yield of 15%. Also noted was that in Southland a 3°C decline in temperature might actually prevent maturation of grain crops.[26]

Table 3: Estimated daily dietary energy intake of the total New Zealand population.

Population group	Average estimated daily dietary energy intake in kJ (nutrition survey data[32,33])	Population size (Q4 2021 estimates[34])	Total kJ per day (billion)
Adult men (15+ years)	10,380	2,041,970	21.2
Adult women (15+ years)	7,748	2,105,180	16.3
Children* (<15 years) – males	7,573	496,930	3.76
Children* (<15 years) – females	6,703	470,720	3.16
Total	–	5,114,800	44.4 ** (8,686 kJ/person/day)

Notes: * We used the energy intakes for the 5–6-year-old age groups. Intakes for the <5-year age group were not collected in the survey data. For the 11–14-year age group, the intakes were fairly similar to adults (boys: 10,303; girls: 8,323).[33]
** We recognise that this total might be slightly below the ideal for planning purposes since some of the adult survey respondents reported food insecurity, some people may have been dieting to control their weight at the time of the survey, and because of under-estimation of food intakes associated with the use of food diaries.[46]

Table 4: Food exports and available dietary energy estimates for New Zealand after adjusting for unavoidable food waste (inedible components) and avoidable food wastage (as per Table 1).

Food export category (if over 10,000 tonnes per year)	Average annual exports (tonnes) – 5-year average ending June 2020*	Greatest contributor to weight	Daily food energy equivalents (kJ/day)* [% of daily required for all New Zealand population, adjusted for waste]	Further details
Dairy products (ordered by potential % of total dietary energy)				
Total milk, powder	1,895,691	Code=0402210019; "Dairy produce; whole milk powder, concentrated, not containing added sugar or other sweetening matter, of a fat content exceeding 1.5% (by weight), n.e.c. in item no. 0402.21"	218%	Harmonised systems "dairy products" AND "milk". Exports recorded in kgs.
Butter	470,001	Code=0405100001; Dairy produce; derived from milk, butter, unsalted	82%	Harmonised systems "dairy products" AND "butter"
Cheese	336,226	Code=0406900011; Dairy produce; cheese, cheddar (other than in tins, not grated, powdered or processed)	33%	Harmonised systems "dairy products" AND "cheese"
Total milk, liquid	222,131**	Code=0401200901; Dairy produce; milk and cream, not concentrated, not containing added sugar or other sweetening matter, of a fat content, by weight, exceeding 1% but not exceeding 6%, UHT milk	3.2%	Harmonised systems "dairy products" AND "milk". Exports recorded as litres.
Other dairy product, including yoghurt, buttermilk, whey	140,069	Code=0403901901; Dairy produce; buttermilk powder, produced by a spray process, concentrated or sweetened, with or without flavouring, added fruit, nuts or cocoa	1.3%	Harmonised systems "dairy products" remaining not fats
Meat products				
Lamb and mutton, including edible offal and processed meats	398,267	Code=0204420001; Meat; of sheep, lamb cuts with bone in, frozen (excluding carcasses and half-carcasses)	18%	Harmonised systems "meat" AND "bovine" and "offal" AND "sheep" but not fats
Beef and veal, including edible offal and processed meats	473,405	Code=0202300001; Meat; of bovine animals, beef cuts according to the New Zealand Meat Producers' Board definition, of cow, steer and heifer, boneless, frozen	16%	Harmonised systems "meat" AND "bovine" and "offal" AND "bovine" but not fats

Table 4 (continued): Food exports and available dietary energy estimates for New Zealand after adjusting for unavoidable food waste (inedible components) and avoidable food wastage (as per Table 1).

Food export category (if over 10,000 tonnes per year)	Average annual exports (tonnes) – 5-year average ending June 2020*	Greatest contributor to weight	Daily food energy equivalents (kJ/day)* [% of daily required for all New Zealand population, adjusted for waste]	Further details
Marine food products				
Fish	185,825	Hoki	3.3%	Exports Summary data—Quantity of Principal Exports
Molluscs	61,106	Code=0307430013; Molluscs; squid, frozen, whole	1.3%	Harmonised systems “molluscs”
Fruit				
Kiwifruit	512,435	0810500019; Fruit, edible; kiwifruit, green fleshed, fresh	4.5%	Harmonised systems “kiwifruit”
Apples	362,537	Code=0808100042; Fruit, edible; apples, Royal Gala, fresh, whole fruit	3.4%	Harmonised systems “apple”
Avocados	18,508		0.7%	Harmonised systems “avocado”
Vegetables				
Onions	175,110		1.0%	Harmonised systems “onions”
Potatoes (fresh, frozen or otherwise prepared)	97,334		0.9%	Harmonised systems “potatoes”
Peas (frozen)	38,507		0.7%	Harmonised systems “vegetable” search
Sweetcorn (frozen)	11,270		0.2%	Harmonised systems “vegetable” search

Table 4 (continued): Food exports and available dietary energy estimates for New Zealand after adjusting for unavoidable food waste (inedible components) and avoidable food wastage (as per Table 1).

Food export category (if over 10,000 tonnes per year)	Average annual exports (tonnes) – 5-year average ending June 2020*	Greatest contributor to weight	Daily food energy equivalents (kJ/day)* [% of daily required for all New Zealand population, adjusted for waste]	Further details
Other (converted from litres to tonnes)**				
Wine	257,006		4.4%	Harmonised systems "wine"
Beer	33,307		0.2%	Harmonised systems "beer"
Spirits***	12,104		0.2%	Harmonised systems "spirits"
Totals				
Total kJ per New Zealand citizen	–		34,098 per New Zealand citizen per day	As per population groups in Table 1
Excess factor relative to current intakes	–		3.93 times dietary energy intakes	See Table 1

Notes: * We used the 5-year average for exports between July 2016–June 2020 to avoid too great an impact from COVID-19 disruptions.
** The export values were converted from litres to tonnes using the following values: Assumed density of liquid milk products at 1.035kg/L; wine at 1.011kg/L; spirits at 0.989kg/L; and beer at 1.030kg/L.
*** Export volumes recoded in "L.Alc" converted to litres using the lowest percentage alcohol in the category range.

Table 5: Daily dietary energy provided by major food export categories relative to the daily dietary energy intakes of the current New Zealand population and after three nuclear winter scenarios.

Major food export group (from Table 4)	Weight of annual food exports in tonnes (from Table 4)	Percentage of total New Zealand population energy intake (business-as-usual) (%)	Percentage of total New Zealand population dietary energy intake from diverted food exports after various nuclear winter scenarios (as per Table 2) (%)		
			8% reduction in agriculture	28% reduction in agriculture	61% reduction in agriculture
Dairy products	3,064,118	338%	311%	243%	132%
Meat products	871,672	34.1%	31%	25%	13.3%
Fruit	893,480	8.6%	4%	3%	3.3%
Alcohol	302,417	4.8%	8%	6%	1.9%
Marine food products	246,931	4.6%	3%	2%	1.8%
Vegetables	322,221	2.7%	4%	3%	1.1%
Total	5,700,839	393%	361%	283%	153%
Total kJ available	–	63,658,104	58,565,456	45,833,835	24,826,661
Total kJ per person per day available	–	34,098	31,370	24,551	13,298

Table 6: Domains (other than agriculture) of relevance to food security vulnerabilities in a post-nuclear war/ nuclear winter setting.

Domain (largely adapted from Zeihan[47])	Potential details relevant to post-nuclear war food security vulnerabilities requiring further research
Transport	Food is transported internally in New Zealand by rail, truck and van. Except for the North Island Main Trunk railway and suburban rail systems (which are electrified), these transport modes are highly dependent on imported liquid fossil fuels. The exploratory work in New Zealand on electric-milk tankers[48] and hydrogen-powered trucks[49] is still at a very early stage. In a post-war setting, some existing electric cars and vans could be re-purposed for food delivery, but possibly food production would need to be intensified closer to cities and towns. Severe fuel shortages could require a return to cattle drives where cattle are herded along roads from farms to abattoirs in towns and cities.
Finance	An operational financial system in New Zealand could be threatened by nuclear war, with a risk of collapse.[26] Unemployed and retired people would need money to buy food from farmers, food processors and food distributors. Therefore, central and local governments might need to have backup food rationing systems and systems for prioritising food supplies to essential workers and those at greatest need. Fortunately, the New Zealand Government obtained some valuable experience with rapidly providing mass welfare support during the COVID-19 pandemic—but the scale of a post-nuclear war situation would probably be vastly greater and longer lasting. Appropriate financing may also be needed to assist the agricultural sector in diverting crops suitable for human food that are currently used for animal feed and other purposes. For example, an estimated 78% of cereals produced in New Zealand are used for livestock feed (i.e., much of the wheat, maize and oats).[50] Furthermore, some of the remaining 22% of cereals could be used more efficiently to feed humans, e.g., if more of the barley crop was used for making flour rather than being used to make beer and spirits. Fodder beet (a type of beetroot) and forage brassicas (e.g., canola, radish, turnip, swede, and kale) could also be converted from stock feed to human food. Alternatively, this forage cropping land could be used for other food crops.
Energy	In addition to energy for transport (see above), energy is needed to run agricultural machinery. Some of this is electrical energy (e.g., for irrigation systems and milking sheds), but much of the machinery uses imported diesel fuel. Substitutes for this diesel are fairly minimal with low levels of biofuel production (made from whey, tallow, and used cooking oil,[51] including with some of the refining done offshore). One New Zealand refinery has even converted away from biodiesel production to food oil production.[52] Liquid biofuels may need to be prioritised for the least vulnerable and most efficient food crops (for dietary energy per hectare) such as frost-resistant grains and vegetables (see the Appendix). The end of oil refining capacity of the Marsden Point refinery in 2022 has unfortunately closed off one source of partial fuel self-sufficiency. That is there is no longer capacity to refine onshore "the light crude oil from Taranaki—which could meet about 15% of our current demands."[53] A further risk to electrical grids (and telecommunications) in New Zealand is that an electromagnetic pulse (EMP) from nuclear attacks on facilities in Australia might have spill-over impacts on New Zealand. The probability of such attacks on Australia in a nuclear war are highly uncertain, as is also the impact of EMP itself given it is very dependent on the altitude of the explosion.[54]
Industrial materials	Many inputs into agriculture are imported, including much of the fertiliser, pesticides, animal health pharmaceuticals, and spare parts for agricultural machinery. New Zealand is a major seed exporter for some food crops (e.g., radishes, carrots and beets[55]) but is also reliant on imports.
Manufacturing	Although New Zealand does make some of its own nitrogen fertiliser, it is dependent on imports for phosphate-based fertiliser.[56] The capacity to manufacture replacements for imported materials (as per those in the row immediately above) is uncertain.

Table 6 (continued): Domains (other than agriculture) of relevance to food security vulnerabilities in a post-nuclear war/nuclear winter setting

Domain (largely adapted from Zeihan[47])	Potential details relevant to post-nuclear war food security vulnerabilities requiring further research
Trade (international)	If post-war trade was able to be re-established with regional neighbours such as Australia and Indonesia, then these countries could provide some liquid fuels and machinery parts used for food production in New Zealand. If so, New Zealand could strive for some ongoing food exports to these countries so that imports could be paid for. Trade with Pacific Island nations could include the export of coconut oil, sugar and dried fish to New Zealand, with coconut oil also being a potential diesel substitute.
Societal functioning	Given all the potential impacts referred to in this table, especially if there is an end to international trade and risk of financial collapse, New Zealand society could be extremely shocked after a Northern Hemisphere nuclear war. Factors such as the competence of central and local government and the quality of communication by societal leaders would also probably be very important. This is a complex area to research (with relevant New Zealand writing being fairly out-of-date[57]), but new work could build on studies of the other domains in this Table, and studies of how New Zealand and other societies has responded to other shocks (including the COVID-19 pandemic). Some authors suggest a possible refugee influx to New Zealand and Australia after a nuclear war.[30] Nevertheless, it seems plausible that the difficulties with access to shipping in a post-war environment could substantially constrain the arrival of such refugees. Even so, a full analysis of food supply issues under a range of plausible circumstances might give an indication of how many refugees New Zealand could readily absorb. It is also possible that with imported fuel shortages impacting the use of agricultural machinery, refugees could help with providing additional manual labour for food production.

Impact of nuclear winter scenarios

The impacts on food availability from currently exported food after the various nuclear winter scenarios (as detailed in Table 2), are shown in Table 5. In the most severe scenario for climate impacts of a nuclear winter (a 61% reduction in food production), diverted food exports could still provide 1.5 times the current dietary energy intakes for the whole New Zealand population (or 13,298kJ [3,178kcal] per person per day). In the much smaller regional nuclear war scenario (5Tg of stratospheric soot, 8% reduction in food production), diverted food exports could still provide 3.6 times the current dietary energy intakes of the population.

Discussion

Main findings and interpretation

This preliminary analysis suggests that New Zealand's current food production for export is theoretically able to provide an excess of dietary energy for the whole population, even after a severe nuclear winter that reduced food production across-the-board by 61%. As such, this baseline excess food production capacity would also be a resilience factor after other sunlight-reducing planetary catastrophes such as large volcanic eruptions and asteroid/comet impacts. Furthermore, given the breadth of food production in New Zealand, there are no survival-critical food products that would be missing from the national diet after such catastrophes. At any point in time some of these exported foods are already available in warehouses and in shipping containers awaiting export. For example, if 10% of annual export production is in this pre-export state, it would be enough to provide dietary energy for all New Zealand citizens for around 4.7 months (if appropriately distributed).

Despite the preliminary estimates in this study, the New Zealand agriculture sector is extremely interconnected with other key systems in modern technological society. As such it can be considered at risk of various levels of collapse from lack of imports (e.g., diesel, fertiliser, pesticides, seeds, and machinery parts). Similarly, if the financial system collapsed (e.g., due to its dependency on overseas cloud computing), then farmers would not be paid for food production, and they may shift to providing for themselves and bartering

with local communities. Social disruption could also arise with mass unemployment from the collapse of the export/import trading economy, and this could impair the orderly production and distribution of food supplies. Therefore, there is a need for further research on all interlinked domains considered by Zeihan,[47] in addition to international trade and societal functioning, as detailed in Table 6.

Study strengths and limitations

A strength of this preliminary study is that it is the first one to take such an in-depth bottom-up look at food security in New Zealand after a nuclear winter. That is, other analyses have taken a higher level approach to dietary energy availability in the business-as-usual case[58] (i.e., 9569 kcal/per person/day in 2013 for New Zealand), and in the post-nuclear-winter case.[28,30] Nevertheless, our work is still preliminary given we have not explored all the important other sectors that agriculture, food processing and food delivery are interlinked with (as per Table 6). Other notable limitations of our analysis include the following:

- It does not consider the size of New Zealand's non-export food economy—due to its vastly greater complexity. This domain includes the food produced for the domestic market, household level production (e.g., vegetable gardening and on lifestyle blocks), and citizen harvesting food from the environment (e.g., fishing, hunting and shellfish gathering). Nevertheless, one estimate for 2018 was that the country produced 7,768 kilotonnes of food, of which 2216 kilotonnes (28.5%) was for the domestic market. However, this previous estimate did not consider stocks from previous years and production waste (i.e., losses during transportation and storage).[50] Also, our analysis only considered major food export domains by ignoring average annual food exports of under 10,000 tonnes (i.e., excluding such food exports as: beans, berry fruits, brassicas, capsicums, carrots, citrus, eggs, honey, pears, squash, and tomatoes).[50]
- The nuclear winter impacts involved various simplifying assumptions. For example, the estimates from Xia et al.[30] were for selected crops and marine fish and we extrapolated from these to across-the-board reductions in food productivity. Although the model by Xia et al. considered impacts on "surface air temperature, precipitation and downward direct and diffuse solar radiation", it did not consider potential damage to agriculture from increased ultra-violet light after a nuclear war.[59] There may also be complex nuclear winter effects on sea-ice and oceans that impact on fisheries for very long periods.[31]
- The nutrition analysis was only for dietary energy and so further work could consider the scope for achieving nutritionally balanced diets. Nevertheless, protein availability would not seem to be a major concern, given the current extent of exported dairy products, meat and marine products. New Zealand is also self-sufficient in egg production, and produces grains and legumes that are protein sources (e.g., beans for the export market).[50]

Potential implications for further research and resilience building

Given the risks and uncertainties, further work into food security during nuclear winter and other sunlight-reducing scenarios is desirable, and could focus particularly on the issues detailed in Table 6. More specific research domains within the agricultural sector are detailed in Table A1 in the Appendix. Some of these also have the potential co-benefit of strengthening the resilience of New Zealand's food systems, following Tendall et al's definition of food systems resilience, "including social, economic and biophysical processes operating at many scales".[60]

Conclusions

This analysis suggests that this country could theoretically have excess food production capacity, even after a severe nuclear winter scenario. But this benefit could be very short-term if the agricultural system was not made more resilient to potential lack of international trade and socio-economic collapse in a post-war setting. As such, further research is needed to clarify agricultural impacts and the role of such catastrophes on the interlinked domains of energy, transport, manufacturing, finance, industrial materials, trade and societal functioning.

COMPETING INTERESTS
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Appendix: Potential research areas for enhancing food security resilience in New Zealand after a nuclear winter and other sunlight reducing catastrophes (for further detail on the vulnerabilities of other sectors see other work[53,61])

Domain	Additional details
Food production	
Focusing more on producing frost-resistant crops	To maximise chances of ongoing food production in a nuclear winter, there is a case for a particular focus on ensuring adequate supplies of frost-resistant crops to provide for a majority of the population's dietary needs. Examples of these (many of which New Zealand already produces to some extent), include:[62] **Moderate frost hardiness (-4 to -7 °C):** Winter oats*, spring cereals, cauliflower and broccoli leaves, kale*, white and spring cabbage, sugar* and fodder beet*, onions, swede*, spring canola*, winter lupins*, carrots, winter lettuce, and parsnips. **Reasonable frost hardiness (-7 to -10 °C):** Winter barley*, winter canola*, winter field beans*, winter linseed*, savoy cabbage, spinach, and rhubarb crowns. **Good frost hardiness (-10 to -15 °C):** Winter wheat*. **Very frost hardy (colder than -15 °C):** Winter rye*. *These crops can be used as feed crops for various types of livestock, but they can also be used to directly feed people. In addition to the benefits of frost-resistance, none of these crops require refrigeration and typically require less additional processing than dairy and meat products. Also, in times of extreme socio-economic hardship, grains don't need to be turned into bread etc, as the seeds can be eaten directly after cooking.
Enhanced soil protection	Research could consider the most cost-effective approach to enhance soil protection —especially of land potentially available for frost-resistant crops near cities. Enhanced protection of soils has previously been argued for New Zealand on general food security grounds.[50] Options include increasing tree planting on erosion-prone land and better control of introduced mammalian pests (e.g., deer, pigs and goats). The protection of high-quality soils from urban development may also contribute to greater resilience and a national policy statement for the protection of the 15% of the country's land considered to be "highly productive" was produced in 2022.[63] Reducing soil erosion would also help protect other food sources: shellfish and other kaimoana (seafood) in estuaries, and mahinga kai (e.g., eels) in rivers and streams.
Increased electrification of agriculture and food systems	Research could explore how to make the agricultural sector less reliant on imported fossil fuels, e.g., via increasing numbers of electric vehicles and greater electrification of farm machinery and food processing machinery. Using hydro-generated electricity for hydrogen fuel production (e.g., for trucks and trains) in New Zealand,[64] could be given further attention. Although not as energy efficient as electric and diesel vehicles, hydrogen could still provide an additional level of resilience.
Greater agricultural self-sufficiency	Research could study ways to support the agricultural sector to become less reliant on imported fertilisers and imported feeds (e.g., palm kernel expeller).
Optimising land-use in general	Research could examine how to support "best fit" land-use change so that farming systems are optimally suited to local soils, geography, and climate. This could enhance food security and resilience to climatic shocks.[65]
Increased urban food production	Research could explore how to increase urban food production by households (e.g., fruit, vegetables, and poultry), in community gardens, and by local Māori agribusiness that can supply food directly to iwi members.[66] The Government-funded think tank Te Puna Whakaaranui has argued that "empowering communities to produce and distribute food is a low cost, culturally inclusive approach to food security".[67] This think tank cites local examples such as the Hauora Kai Co-Op[68] and WELLfed.[69] Priority urban crops to promote (from a nuclear winter perspective), could be the frost-resistant vegetables detailed in the first row of this table.

Appendix (continued): Potential research areas for enhancing food security resilience in New Zealand after a nuclear winter and other sunlight reducing catastrophes (for further detail on the vulnerabilities of other sectors see other work[53,61])

Domain	Additional details
Food production (continued)	
Seed banks	Research could examine the value of seed banks for seeds of the frost-resistant crops that New Zealand currently imports.
Differing types of food and food use	
Plant-based diets	Research could explore how to best promote a faster shift to more plant-based diets as these are typically more sustainable, lower cost and healthier as per various New Zealand studies.[70–72] This could assist in increasing the national self-sufficiency of the frost-resistant grains and vegetables detailed in the first row of this table.
Enhanced marine food supply	Research could consider the expansion of marine food reserves through better management of coastal fisheries and expansion of the number and size of marine reserves. It has been estimated that "…effective pre-war management that rebuilds fish biomass could ensure a short-term catch buffer large enough to replace ~43± 35% of today's global animal protein production".[29] Increased consumption of discarded bycatch and marine offal, could also increase food supplies for people in a post-war setting. Research is already underway of the expansion of commercial seaweed production in New Zealand[73] and this food source could potentially be scaled up in some coastal areas. Nevertheless, commercial fishing is extremely dependent on imported diesel and so may only be viable in a post-war scenario where local biodiesel production was substantial. It is also dependent on foreign shipping crews (e.g., from Russia and Ukraine).
Food waste reduction	Research could further examine ways to reduce food waste at all levels in the food system, given the New Zealand data on the substantial size of this problem.[38] Reducing household level food waste now could have immediate cost-saving benefits for citizens and reduce greenhouse gas footprints.

Constraints on medication-based inflammatory bowel disease therapy in Aotearoa New Zealand—why medication adherence is important

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ABSTRACT

The therapeutic landscape for treating Inflammatory Bowel Disease (IBD) in Aotearoa New Zealand had remained largely unchanged for about a decade; however, just this year, two further biologic medications became available. In an international context, these medications are not exactly new, and several other highly efficacious, modern medications and treatment paradigms are available overseas but not in New Zealand. Medication adherence (MA), alongside factors including (relaxation of) medicines funding criteria, specialist availability, IBD awareness in primary healthcare etc., contributes to good patient care. Hence, we contend that MA remains of particular importance for New Zealand patients with IBD to derive maximum benefits from the limited therapeutic options available. Moreover, increased research and interventions for promoting MA, in IBD especially, are crucial.

Inflammatory bowel disease (IBD) is a chronic disease of the gastrointestinal tract comprising Crohn's disease (CD), ulcerative colitis (UC) and IBD-unclassified (IBD-U).[1,2] IBD is of unknown origin, but is characterised by chronic, relapsing and remitting gut inflammation due to an interplay between genetic susceptibility and environmental elements resulting in maladaptive immune responses.[1,3,4] There is no cure for IBD, with the main therapy being constant monitoring and a careful life-long medication regimen, besides surgery and other interventions. As IBD is diagnosed mainly at a young age, it places a considerable social burden on patients' education, careers and relationships etc., alongside its impact on their health.[5] Moreover, as well-controlled IBD has a minimal impact on the lifespan, patients bear the disease burden for the majority of their lives.

IBD is characterised by periods of active disease, flare-ups and quiescent times with varying impact on patients' wellbeing. During times of active disease, patients with IBD might face a range of symptoms including (bloody) diarrhoea, urgency/tenesmus, constipation/loading, abdominal discomfort/pain, weight loss etc., limiting their quality of life (QoL) and overall productivity.[1] Furthermore, uncontrolled IBD might lead to complications including strictures, fistulae or abscesses, amongst others. Patients with IBD may also experience extra-intestinal manifestations, which worsen patients' QoL, such as inflammation in the eye (e.g., uveitis/episcleritis), skin (e.g., pyoderma gangrenosum and erythema nodosum) and joints (e.g., ankylosing spondylitis), alongside several others including pancreatitis and osteoporosis.[1,6]

Moreover, IBD poses considerable costs to the patient and society. In New Zealand, the yearly cumulative direct and indirect (loss of productivity etc.) costs of IBD amounted to approximately $245 million NZD, as at 2017,[7] and costs are likely to have risen since then with increased prevalence and general economic inflation.

Global burden of IBD

IBD is a global disease, with its incidence/prevalence expected to grow particularly as global life expectancy rises.[5] However, there is a marked difference in its geographical burden as industrialised Western countries have much greater IBD incidence/prevalence than others, although developing countries have higher growth rates of IBD.[5,8,9]

IBD is most prevalent in Europe and North America, with high levels of Crohn's disease (CD) and ulcerative colitis (UC) of 319 per 100,000 in Canada and 505 per 100,000 in Norway, respectively.[9] Across Europe, CD and UC prevalence is as high as 213 and 294 cases per 100,000 persons, respectively.[10] Nonetheless, incidence rates

in developing regions, such as Africa, South America and Asia, have been on the rise for the past three decades. Case in point, Brazil has an annual growth in CD and UC incidence of 11.1% and 14.9%.[9] Similarly, in Taiwan, CD and UC incidence rises by 4% and 4.8% yearly.[9]

IBD incidence in Western countries is plateauing, whilst that of developing countries is accelerating.[1,9] Nonetheless, the disease burden remains greatest in the "Western" world with prevalence exceeding 0.3% in most nations of Europe, North America and Oceania.[9] Seventy-five thousand Australians have IBD with over 1,600 new diagnoses made annually; whereas, in New Zealand, IBD prevalence stood at 20,792 people as at 2017, and by 2028, this value will have doubled due to an annual growth rate of 5.6%.[1,7,11]

IBD incidence has increased in tandem with the development and "Westernisation" (in dietary/societal norms etc.) of industrialising nations.[3,5,8,10] Diet has been associated with the development of IBD, especially consumption of high sugar, fat and processed foods, which are common in Western diets.[5] The higher prevalence of IBD in Europe and North America, whose countries have been industrialised for longer, as compared to Asia and Africa is in consonance with this development-incidence trend.[9] Thus, it can be expected that IBD rates will grow as even more countries develop in the coming decades; further heightening the global impact of the disease.[5]

IBD therapy: constraints in New Zealand

IBD requires complex lifelong therapy impacted by various factors and thus ideally provided by a multidisciplinary team composed of a gastroenterologist, nurse (IBD, stoma therapy specialist), dietician, pharmacist, colorectal surgeon, psychologist and others.[1] The overarching purpose of therapy includes: inducing and maintaining disease remission; decreasing complications (e.g., abscesses, strictures, fistulae); bettering patients' QoL; reducing medication toxicity; re-establishing and sustaining good nutrition, as well as minimising the risk for surgery and/or hospitalisation.[2]

Classes of medications used in IBD therapy include: 5-aminosalicylic acid drugs - 5-ASAs (e.g., sulfasalazine, mesalamine); corticosteroids (e.g., prednisone/prednisolone, budesonide); and immunomodulators (e.g., thiopurines—azathioprine, 6-mercaptopurine (6-MP), and methotrexate besides the newer ozanimod).[12,13] Others are: antibiotics (e.g., ciprofloxacin, metronidazole) and, more recently, biologic agents (e.g., infliximab [IFX], adalimumab [ADA], certolizumab pegol [CZP], golimumab [GOL], [all of which are TNF inhibitors], natalizumab [NAT] [α4-integrin inhibitor], vedolizumab [VDZ] [α4b7 inhibitor] and ustekinumab [UST] [IL-12/IL-23 inhibitor]), and Janus kinase inhibitors (JAKi) (tofacitinib, upadacitinib and filgotinib).[4,12–14] Additionally, exclusive enteral nutrition (EEN), a dietary intervention, is also used in IBD therapy.[1] The combinations of medications prescribed depend on factors such as disease activity, therapy target (e.g., attain vs maintain remission), side effects and comorbidities, amongst others; thus, other medicines might also be utilised as the disease progresses. Only some of the aforementioned medicines are publicly funded in New Zealand (see Figure 1).

Conventional IBD therapy, particularly in New Zealand, takes a "bottom-up"/"step-up" approach entailing the incremental usage of more affordable—symptom controlling—medications, with gradual escalation to (more expensive) disease pathophysiology modifying therapeutics until the target disease outcomes are attained (see Figure 2).[7,15,16] However, some specialists argue that such an approach focusses on remedying already entrenched disease, often missing the "window of opportunity" where prevention or reversal of damage to the bowel might best be possible.[17] Therefore, other treatment paradigms including the "top-down" approach are recommended. This entails the use of top-disease pathophysiology modifying drugs (e.g., biologics alone/alongside immunomodulators) from the outset of therapy to arrest disease progression and swiftly attain remission, following which the medications are gradually withdrawn.[15,16,18] Central to this strategy is providing patients with timeous specialist (gastroenterology) care; but in practice, it can take months for patients to access publicly funded specialist care in some places, like New Zealand, due to specialist workforce limitations.[11] Hence, greater awareness at the primary care level leading to timeous specialist referrals for diagnosis is essential. Also, disease monitoring is important both to measure the effect of therapy and to assess adverse side effects concomitant with the powerful medications utilised. However, due to the prohibitive costs of advanced medications, and specialist shortages, amongst others, "bottom-up" therapy is the sole option for clinicians and patients in many (non-Western) countries, including New Zealand.

Figure 1: Medications used in IBD therapy and funding status in New Zealand.

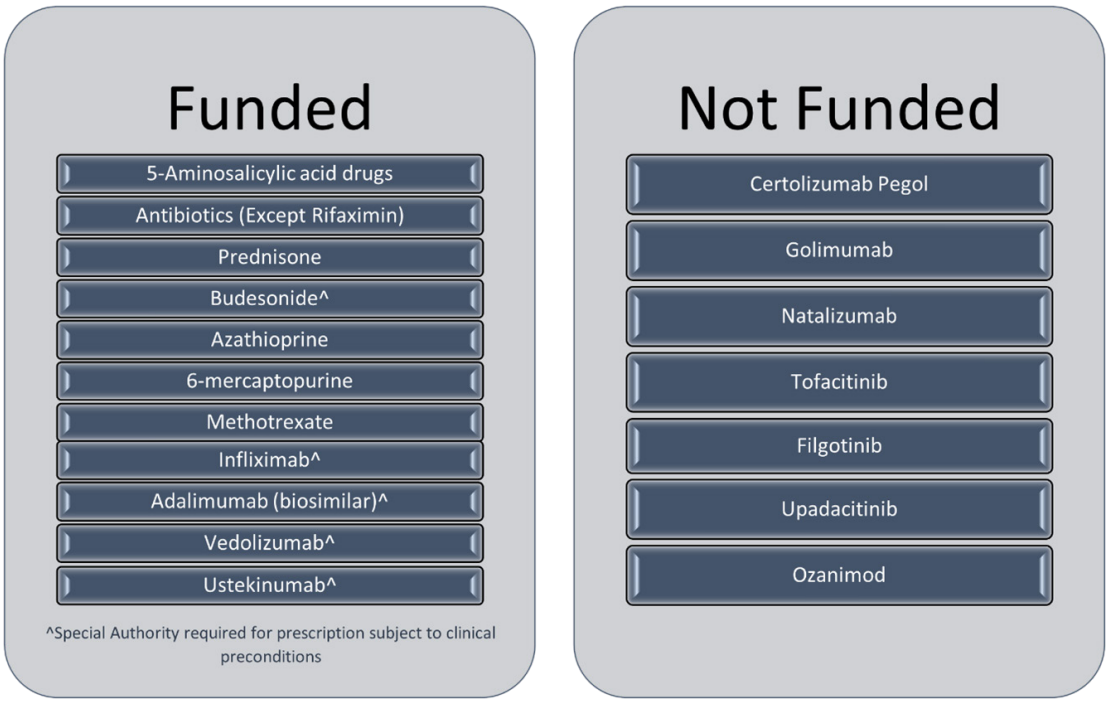
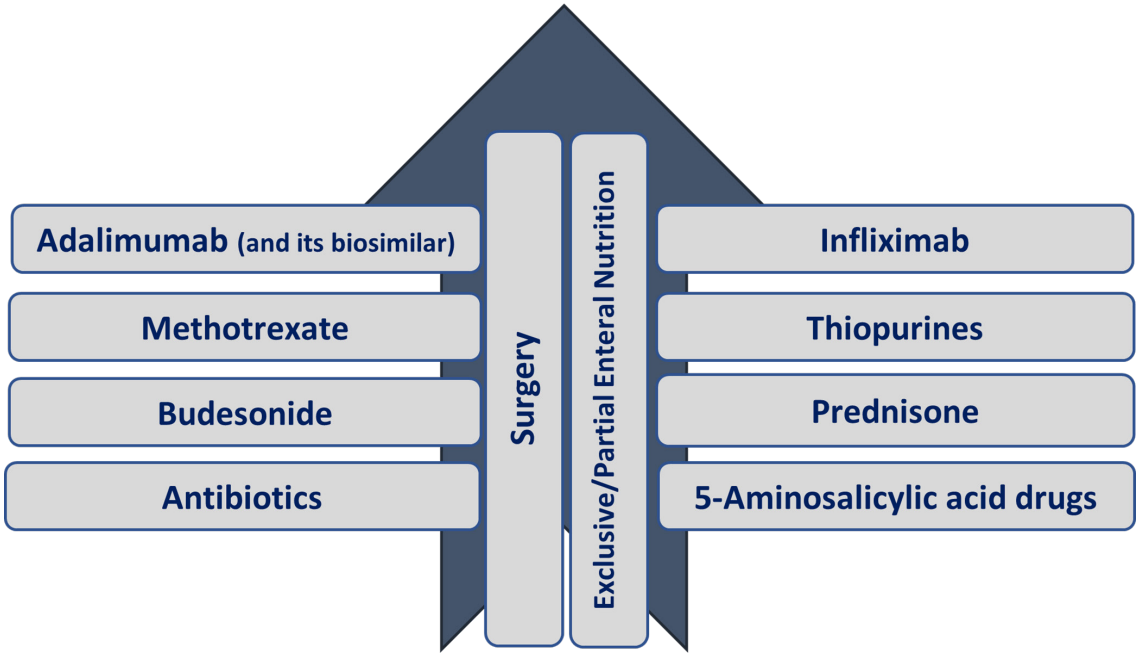


Figure 2: IBD medication use in conventional therapy in New Zealand.



Adapted (in part) from Kahui, Snively and Ternent (2017)[7]. Arrow indicates therapy escalation in the "bottom-up" approach. Surgery and nutritional interventions might be necessary at any time in the disease course and medication therapy might continue thereafter.Notes: Medications list is not exhaustive, and medicines placed side-by-side are not necessarily used in tandem.

A critical review of the literature found that studies reported mixed results when assessing the "top-down" vs "bottom-up" approaches, with results varying based on factors including: medications used, therapy initiation point, outcomes assessed etc.[18] Nonetheless, "top-down" therapy shows marked promise; for instance, some studies found using joint biologic and immunomodulator therapy early in adult CD to be better at achieving certain patient outcomes (e.g., remission, mucosal healing) than the "step-up" approach.[18] Notwithstanding, more research is needed to compare clinical outcomes in patients adopting the two approaches, particularly in light of the high costs of top disease pathophysiology modifying drugs amongst other considerations.[1,18] This is also important as the "top-down" approach holds the risk of "overtreating" patients,[17] who might never have faced disease progression but cannot be identified *ab initio* as predicting disease progression is difficult, leading to unnecessary costs and side effects/risk exposure.

A major pivot of advanced IBD therapy is the use of biologics, which are disease pathophysiology modifying IBD therapeutics used for inducing and maintaining disease remission. Their availability is particularly limited in non-Western countries and their prescription is typically restricted.[1] In New Zealand, the only biologics approved for IBD therapy are IFX, ADA, VDZ and UST, but special authority from the Pharmaceutical Management Agency (PHARMAC) must be obtained to receive funding.[19–21] These biologics are approved for use only as IBD escalation therapy; and certain clinical criteria must be met e.g., severe active disease (with specific evidentiary indicators), failure of standard (step-up) therapy, when surgery is not clinically advisable etc., for publicly-funded prescription to be permitted.[19,21] Moreover, as these criteria do not involve therapeutic drug monitoring, this provides limited flexibility in further prescription of biologics in cases of low biologic drug levels in patients. Other use of these medications would require patients to pay for them, at significant out-of-pocket cost. Nonetheless, other therapeutics are publicly funded and unrestricted, including immunomodulators e.g., azathioprine, 6-mercaptopurine, methotrexate; 5-ASA medications; and (some) corticosteroids, amongst others.

The New Zealand Society of Gastroenterology (NZSG) notes that the range of medications approved for use in New Zealand is limited as compared to other countries where more novel therapeutics are available.[11] This in turn makes it extremely important that IBD patients adhere to the medication regimen, so disease progression is slowed, halted or reversed as there are limited advanced medications available/accessible to treat complex disease.

In recent years, as a testament to their utility at inducing and/or maintaining remission in IBD, several novel biologic medications have been approved by the US Food and Drug Administration (FDA) and/or the European Medicines Agency (EMA) for use in IBD treatment.[4] The FDA has approved seven IBD biologics (IFX, ADA, CZP, GOL, NAT, VDZ and UST) alongside tofacitinib and others,[14] thus providing US-based clinicians with a range of the most cutting-edge therapeutics to handle advanced disease or, yet still, adopt the "top-down" treatment strategy. We contend that a change in the criteria for public-funding of the top-disease pathophysiology modifying medications to allow for use in early-stage therapy in New Zealand would be beneficial to many patients. Furthermore, the public-funding of even more advanced medicines with different action mechanisms, e.g., anti-integrins like NAT, and JAKi, would provide treatment flexibility as loss-of-response to others like adalimumab (anti-TNF) occurs in some patients.[16] The discrepancy in the availability of biologics between countries is due in no small part to their high cost. Hence, countries with more fully publicly funded health systems, such as New Zealand, typically restrict or do not fund the use of biologics. Noting the costs of newer therapeutics, however, the NZSG suggests that their availability in the country would considerably reduce the financial burden associated with IBD therapy in New Zealand—especially inpatient care and surgery.[11]

Medication adherence in IBD—an important necessity

Given the foregoing, it is especially important that IBD patients adhere to their medication regimens for maximally efficient disease management. MA is "*the process by which patients take their medication as prescribed*".[22] Adequate MA is a major pivot in IBD management and substantially increases the likelihood of achieving desired clinical outcomes for patients, which might allow them to enjoy a better QoL. However, MA in IBD patients is often sub-optimal due to both medical and social factors that impact the patients. Hence, ensuring sufficient MA in IBD poses a substantial

healthcare challenge requiring immediate address.

Up to a third of patients with IBD are insufficiently or non-adherent to their medication regimens, with 12.1% and 13.3% of patients with CD and UC in the Netherlands, respectively; 31.1% of IBD patients in southern New Zealand and 36.2% of IBD patients in South Korea found to have poor MA.[23–25] IBD patients' perceptions of their own MA have also been found to differ substantially from the MA as assessed using standardised tools.[25] Failure to adhere properly to the drug regimen can lead to worse treatment outcomes e.g., flare-ups and complications in turn causing escalation of therapy, including frequent corticosteroid use and surgery, as well as increased morbidity and mortality, disability and health costs.[14]

For context, two-thirds of the costs of UC therapy, in the US, are composed of total pharmacy-related (pharmaceuticals, administration and monitoring) costs and over half of the costs attributable to UC are related to anti-TNF (biologic) medications pharmacy costs.[26] These findings spotlight the medication expenses associated with regular therapy, which, it can be surmised, would increase in cases of non-adherence as the use of more (expensive) disease pathophysiology modifying medications would become necessary. The added costs due to non-adherence by IBD patients are not just those of wasted medicines and escalated therapy e.g., using expensive biologics, but also time and effort of healthcare professionals expended in re-treatment as well as the extra burden on the health system in general.

In New Zealand, there are limited studies into MA in IBD patients, with our research team pioneering such research. Notwithstanding, amongst several issues, MA generally is hampered by challenges of access to publicly funded medicines. PHARMAC notes that medicine access inequities abound, with poverty, poor living conditions, inadequate social support, lower income, and importantly, racism, besides others being associated with worse health access.[27] Evidencing this, Māori, Pasifika and disabled people experience worse access to and utilisation of publicly financed medications than non-Māori.[27,28]

PHARMAC categorises the barriers to medicine access into three: *barriers to healthcare access* such as delayed access, costs, transport etc.; *structural barriers* including organisation of care—for example, accessing appointments, wait times, completing referrals etc.; and *provider capacity* to meet an individual patient's needs (e.g., cultural safety and competency, knowledge and skills etc.).[27]

We recognise that there have been various interventions to promote medication adherence in New Zealand; for example, the Medication Use Review and Adherence Support Service (MUR) available in some areas.[29] A pharmacist interviews patients to assess MA, identify/proffer solutions to their individual barriers to MA and educate them on MA in general. Although patients can join on their own initiative, participation is mostly via GP or nurse recommendation but the criteria for enrolment includes presence of comorbidities, polypharmacy etc.[29] However, the status of such services in the new Te Whatu Ora – Health New Zealand system is unclear. Furthermore, most adherence interventions in New Zealand are targeted at the senior (>60yrs) population; this is unsuited to IBD patients who are diagnosed mainly in youth.

Conclusion

In New Zealand, MA is of extreme importance to IBD patients, especially given the limited therapy options available. Only four biologic agents are publicly funded for use in IBD and, with little flexibility, only for escalation therapy. This effectively precludes the use of the several more cutting-edge and advanced medications (JAKi/biologics) that have been developed in the past few years, despite New Zealand IBD patients often having aggravated disease at the point of diagnosis due to barriers to healthcare access. It also pre-empts the trialling of emerging therapeutic strategies, such as the "top-down" approach, which could lead to better treatment outcomes for patients.

Whilst MA is important to any disease therapy, MA remains *extremely* important in IBD therapy in New Zealand, and countries with similar situations, where public-funding is not readily available for the use of newer advanced therapeutics, including JAKi/biologics, as first line medications. Therefore, IBD patients need to derive maximum benefits from the available therapeutics by sticking to the prescribed medication regimens to avoid the worse outcomes related to poor MA. This is particularly until the therapy options are expanded to include newer therapeutics/treatment paradigms, which we would welcome.

Consequently, we maintain that concerted efforts and investments to support multidisciplinary research into the MA landscape in New Zealand are needed to fill current gaps in the research corpus. Such research would cover adherence levels (and its relation to hospitalisations and demographic factors), costs of non-adherence,

patients' perspectives on adherence and their desired support interventions, the barriers to good adherence, and solutions needed. These should be complemented by public health interventions to help IBD patients practice good adherence. The government is best positioned to facilitate these through its ministries and agencies, and by collaborating with universities and research institutions besides the private sector; although these other entities can and should act on their own initiative. Moreover, we hope that the recently launched Te Whatu Ora – Health New Zealand will feature a robust MA promotion service alongside a strong medicines policy that balances access, equity and cost, as well as a sustainable health workforce. These are all necessary to support the recommendations made to PHARMAC, in their recent review, for them to work more closely with the wider health system to reduce inequities in medicines availability and access.[28] The benefits from MA improvement services would also accrue to patients with diseases other than IBD, presumably resulting in an overall healthier population and fewer health costs in general.

COMPETING INTERESTS
Nil.

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Multiple diabetes autoantibodies following an episode of acute pancreatitis

Rick Cutfield, James AD Shand

The quantification of islet autoantibodies is routine in the investigation of possible autoimmune diabetes. These antibodies are present in the majority of people with type 1 diabetes but are rarely encountered in other diabetes types.[1,2]

Acute pancreatitis (AP) is an inflammatory process that may occur following a variety of pancreatic insults. In severe cases, sufficient pancreatic damage may occur that insulin deficiency results—so-called type 3c diabetes.[3] AP and type 3c diabetes are not usually associated with detectable diabetes autoantibodies.

We present the case of a 51-year-old woman who developed diabetes following AP. She had multiple high-titre diabetes autoantibodies but has not developed typical type 1 diabetes over 16 years of follow-up.

Case report

A 51-year-old woman was admitted to the intensive care unit with severe gallstone pancreatitis. Her haemoglobin A_{1c} (HbA_{1c}) was 41 mmol/mol (normal range (NR) <50 mmol/mol) and her body mass index (BMI) was 24.5kg/m^2. Due to inpatient hyperglycaemia, she was started on a low-dose sulphonylurea.

Two years later, the patient's HbA_{1c} had risen to 86mmol/mol. At that time, the anti-glutamic acid decarboxylase (anti-GAD) titre was >2,000IU/mL (NR <10IU/mL), anti-islet antigen 2 (anti-IA2) titre was 34 U/mL (NR <10 U/mL) and islet cell cytoplasmic antibody (ICCA) titre was 160 juvenile diabetes foundation (JDF) IU (NR <10 JDF IU). A fasting C-peptide was 855 pmol/L (NR 370–1470 pmol/L). Human leukocyte antigen (HLA) typing later demonstrated the DR4, but not DR3, haplotype. Insulin was initiated for presumed type 1 diabetes but was gradually weaned, before being ceased six years later. At this time, the patient's HbA_{1c} was 46mmol/mol. The patient maintained excellent glycaemic control on oral agents for another 5 years before restarting basal insulin when her HbA_{1c} rose to 80mmol/mol. She also developed mild exocrine pancreatic insufficiency requiring enzyme replacement.

Fourteen years after the initial measurements, her anti-GAD titre remains >2,000IU/mL with a persistently positive ICCA but undetectable anti-IA2. Her fasting C-peptide is now 1,587pmol/L.

Discussion

We present the case of a woman who developed diabetes during an episode of AP. She had multiple detectable diabetes autoantibodies including persistently and markedly elevated anti-GAD titres. The aetiology underlying these antibodies is uncertain.

Diabetes antibodies are found in over 80% of people with type 1 diabetes and are thought to relate to immune exposure of intracellular material as opposed to being pathogenic.[1] Low titre anti-GAD antibodies are seen in around 1% of individuals without diabetes, with other diabetes autoantibodies being less frequently encountered.[2,4–6] It is conceivable that the autoantibodies in this individual relate to the background antibody positivity seen in the general population. However, the multiple antibodies and high titres detected make this unlikely.

Another potential explanation for the observed antibodies could be an exceedingly slow course of autoimmune diabetes. Such individuals have been described, though antibody titres tend to decline with time in those cases,[7] whereas our patient maintained high anti-GAD titres over many years. Additionally, we would have anticipated a gradual decline in C-peptide in this case, whereas our patient's C-peptide has in fact improved over time.

We wonder whether the autoantibodies in our case relate to the immune exposure of pancreatic antigens during the inflammatory state of AP. Anti-GAD antibodies have previously been

documented in occasional case reports of people with pancreatitis,[8,9] and we have encountered cases where low titres have been present. There is, however, no literature systematically investigating the prevalence of diabetes autoantibodies following AP.

In summary, we present a woman who had markedly elevated diabetes autoantibody titres following severe pancreatitis. Her clinical evolution has not been in keeping with type 1 diabetes and the degree of antibody elevation observed is much greater than that seen in the population without diabetes or in those with slowly progressive autoimmune diabetes. It is possible that her episode of AP could have unmasked intracellular islet antigens with the subsequent development of pancreatic autoantibodies. Prospective data would be valuable.

COMPETING INTERESTS
Nil.

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Inclusion of ethnicity in Special Authority criteria improves access to medications for Māori and Pacific peoples with type 2 diabetes

Ryan Paul, Rawiri Keenan, Mark Rodrigues, Leanne Te Karu, Penny Clarke, Rinki Murphy, Timothy Kenealy, Joseph Scott-Jones, Allan Moffitt, Ross Lawrenson, Lynne Chepulis

Type 2 diabetes (T2D) now affects approximately 300,000 people in Aotearoa New Zealand, of whom at least two-thirds will likely die from cardiovascular disease (CVD) and/or renal disease (CVRD).[1] Unfortunately, T2D creates some of the greatest inequities for Māori and Pacific peoples[2,3] and the shorter life expectancy of Māori and Pacific peoples with T2D in New Zealand has not improved in the past 20 years.[4] Addressing the modifiable risk factors responsible, including improving access to healthcare and medications that slow progression or prevent CVRD, is critical in eliminating these disparities.[4] This includes removing the inequities in prescribing metformin and statins to prevent CVD and angiotensin-converting enzyme inhibitors (ACEi) or angiotensin receptor blockers (ARB) to slow the progression of renal disease.[5,6]

The greatest change to T2D pharmacotherapeutic care in the last two decades has been the use of sodium-glucose co-transporter 2 inhibitors (SGLT2i) and glucagon-like peptide-1 receptor agonists (GLP1RA). In addition to effectively lowering glucose levels without the risk of hypoglycaemia, these medications lead to weight loss and have actions beyond glycaemic control that reduce the progression of CVRD in people with T2D.[7] Hence these medications have the potential to reduce the burden and inequities in CVRD when used in addition to existing medications. Contemporary international and national guidelines recommend using SGLT2i and/or GLP1RA in all with T2D and high risk of CVRD regardless of their glycaemic control.[8,9] These guidelines also recommend using SGLT2i and/or GLP1RA in those without CVRD if the HbA1c is >53 mmol/mol despite the use of metformin with or without other glucose lowering therapies.[8,9]

After more than a decade of SGLT2i and GLP1RA being the mainstay of treatment of T2D worldwide, PHARMAC finally funded access in New Zealand to empagliflozin (a SGLT2i), from February 2021 and dulaglutide (a GLP1RA), from September 2021.[10] Funded access was initially proposed to be restricted under special authority criteria (SAC) for those with T2D with an HbA1c >53mmol/mol despite regular use of at least one glucose lowering therapy for at least 3 months, and either renal disease (eGFR <60mL/min and/or urinary albumin:creatine ratio >3mg/mmol), or CVD, or a 5-year risk of a CV event of ≥15%. Despite strong evidence of the additive benefits of SGLT2i and GLP1RA on reducing CVRD, funding was limited to either empagliflozin or dulaglutide and not combined use. Although the SAC allowed funded access for one of these agents for high-risk patients with CVRD, there was significant concern that the proposed SAC may widen inequities in access for Māori and Pacific peoples.[11] Hence, after significant lobbying from several areas and further consultation, Māori and/or Pacific ethnicity was added as a specific criterion as an alternative to CVRD. Thereby theoretically improving access for Māori and Pacific peoples without CVRD and/or without the need to assess CVRD risk.

Here, we evaluate the impact of including ethnicity as a specific criterion of the SAC by assessing the prescribing of SGLT2i/GLP1RA by Māori, Pacific and non-Māori/non-Pacific (nMnP) ethnicity in those with T2D with CVRD (including equivalent 5-year CV risk of ≥15%), without CVRD (non-CVRD) and unknown CVRD status. Comparisons are made to prescribing unrestricted therapies such as metformin, ACEi/ARBs and statins as per national guidelines.[8] Metformin was chosen as the only glucose-lowering therapy comparison as it is the only glucose-lowering therapy recommended for all people with T2D regardless of CVRD status.[8] Indications for

use in CVRD were taken to be: SGLT2i/GLP1Ra regardless of glycaemic control, metformin if the HbA1c was >45mmol/mol; ACEi or ARB in those with renal disease (defined as per in SAC) and a statin in those with a serum LDL cholesterol (LDLc) >1.8mmol/L.[8] Indications in those without CVRD were taken to be: SGLT2i/GLP1RA with HbA1c >53mmol/mol despite the use of at least one glucose lowering therapy and metformin if the HbA1c is >45mmol/mol. Statins and ACEi/ARBs were not used for comparisons in non-CVRD given their use is not essential in this group.

Data were obtained from all ProCare, Hauraki, Pinnacle and National Hauora Coalition practices (n=302) for all enrolled patients with a diagnosis of T2D aged 18–75 years (n=53,142; Table 1) including ethnicity, CV risk, laboratory and prescribing data from 1 February 2021 to 31 July 2022). Māori (first) and Pacific ethnicities (second) were prioritised when multiple ethnicities were recorded.

CVRD was defined as the presence of renal disease, CVD or high CV risk as per the SAC (n=24,367). Non-CVRD was defined as those with a normal UACR, eGFR >60mL/min, no documented CVD and a 5-year CV risk <15% (n=12,692). Unknown CVRD was defined when data on their CVRD status were not available (n=16,137). Access to medications (SGLT2i/GLP1RA, metformin, statins and ACEi/ARBs) was defined as the proportion of each ethnicity (Māori, Pacific and nMnP) who received ≥1 script for each medication in the 18-month study period (numerator) from those clinically recommended for their use (denominator). Patients with an eGFR <15mL/min were excluded from analyses of metformin and SGLT2i/GLP1RA in those with CVRD (n=192), given that their use is not recommended in significant renal impairment. Patients with no HbA1c data in the study period were excluded from analyses in those for metformin with CVRD (n=576), and all analyses for non-CVRD (n=8) and unknown CVRD (n=3,297) given the indication for use is glycaemic control above target. Patients treated with metformin with an HbA1c <45mmol/mol (n=1,464 in CVRD, n=1,061 in non-CVRD and n=1035 in unknown CVRD), statins with an LDLc <1.8mmol/mol (n=207 in CVRD) or SGLTR2i/GLP1RA with an HbA1c <53mmol/mol (n=913 in CVRD, n=3 in non-CVRD and n=277 in unknown CVRD) were included in the numerator for each analysis on the presumption that

Figure 1: Prescribing of sodium-glucose co-transporter 2 inhibitors (SGLT2i) or glucagon-like peptide-1 receptor agonists (GLP1RA), metformin, statins and angiotensin-converting enzyme inhibitors (ACEi) or angiotensin receptor blockers (ARBs) by ethnicity and CVRD status in those with type 2 diabetes (nMnP=non Māori, non Pacific individuals).

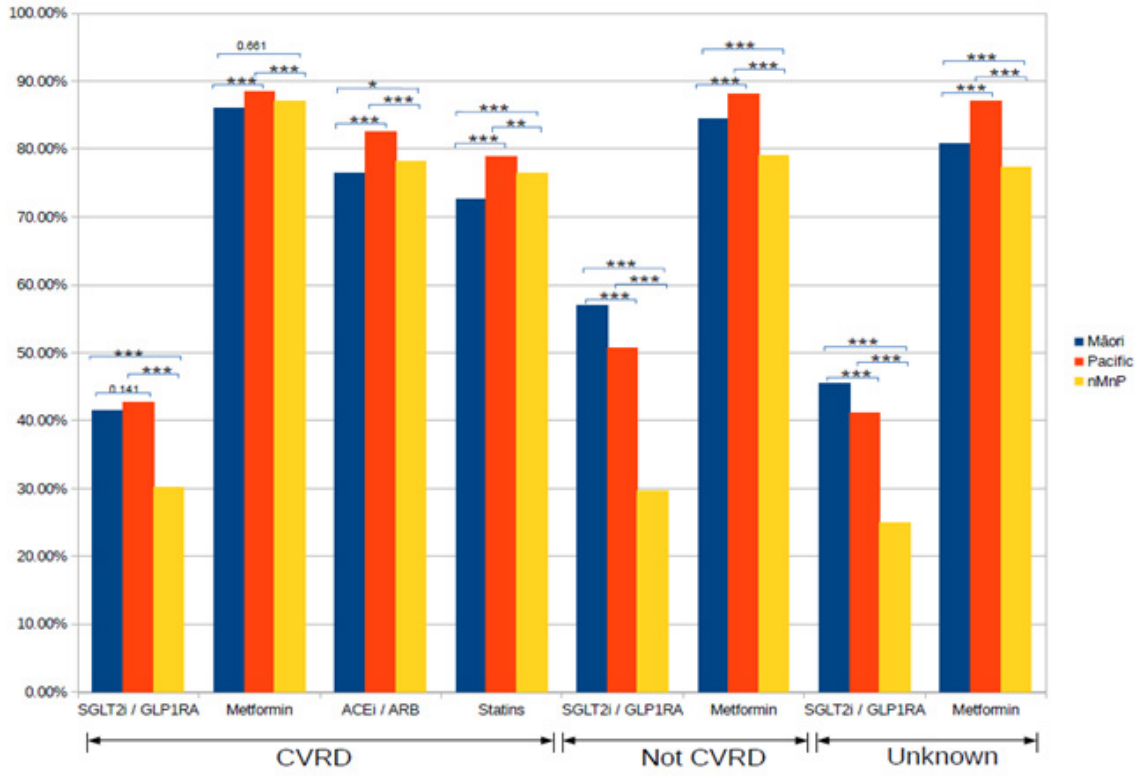

Table 1: Number of T2D patients prescribed SGLT2i/GLP1RA, metformin, statins and ACEi/ARBs by ethnicity and CVRD status.

CVRD	Ethnicity	Total	SGLT2i/ GLPIRA use		Metformin		AcEi/ARB		Stains	
			Prescribed	Indicated	Prescribed	Indicated	Prescribed	Indicated	Prescribed	Indicated
CVRD	Māori	5,629	2,284	5,517	4,084	4,752	3,240	4,240	2,051	2,822
	Pacific	5,741	2,442	5,714	4,643	5,247	3,849	4,660	2,740	3,476
	nMnP	12,997	3,905	12,944	9,648	11,077	6,588	8,420	5,464	7,149
	Total	24,367	8,631	24,175	18,375	21,076	13,677	17,320	10,255	13,447
Non-CVRD	Māori	1,861	670	1,176	1,392	1,597				
	Pacific	2,048	764	1,505	1,707	1,904				
	nMnP	8,783	1,514	5,105	6,451	7,438				
	Total	12,692	2,948	7,786	9,550	10,939				
Unknown CVRD	Māori	3,262	628	1,382	1,711	1,902				
	Pacific	2,541	577	1,404	1,612	1,774				
	nMnP	10,334	1,107	4,446	5,750	6,562				
	Total	16,137	2,312	7,232	9,073	10,238				
All patients	Māori	10,752	3,582	8,075	7,187	8,251				
	Pacific	10,330	3,783	8,623	7,962	8,925				
	nMnP	32,114	6,526	22,495	21,849	25,077				
	Total	53,196	13,891	39,193	36,998	42,253				

they met recommendations for use at a timepoint prior to the start of the study period. Patients on non-funded SGLT2i/GLP 1RA alone i.e., dapagliflozin and liraglutide were excluded (n=61). Data were analysed in R version 4.2 with significance accepted at P<0.05.

Here we show that a much greater proportion of Māori and Pacific peoples with CVRD (~12% more), without CVRD (~20% more) or unknown CVRD status (~15% more) have been prescribed SGLT2i/GLP1RA than their nMnP peers (all P<0.05; see Figure 1). In contrast, Māori were prescribed less unrestricted therapies such as statins and ACEi/ARBs in CVRD (~2–3%), and metformin in unknown CVRD than nMnP peoples (all P<0.05). Pacific peoples with CVRD had greater prescribing for all studied unrestricted therapies than Māori and nMnP peoples, but lower rates of prescribed SGLT2i/GLP1RA than Māori when CVRD was absent or unknown (all P<0.05).

The addition of ethnicity as a criterion for funded access to SGLT2i/GLP1RA appears to have been a useful mechanism in addressing the inequity of access seen with unrestricted therapies. Given this study only assessed initiation of therapy and not dispensing, adherence or tolerance of therapy or its effect on outcomes, further research is needed to assess the impact of the SAC. The effect on outcomes is important because it will likely be at least several years before any impact of greater prescribing of SGLT2i/GLP1RA on current inequitable outcomes such as CV events, dialysis, and premature death can be determined. Moreover, our findings show that further actions are required to eliminate inequities for those with T2D and CVRD. Indeed, it is concerning that approximately one

in four people with T2D and CVRD are not receiving either metformin, statin or ACEi/ARB therapy, approximately two-thirds are yet to be prescribed SGLT2i/GLP1RA, and dual SGLT2i/GLP1RA therapy remains unfunded. With ongoing workforce and COVID-19 pressures affecting the health system, changes in models of care are likely needed alongside targeted interventions such as education and data dashboards to prioritise and assist prescribers (including nurse and pharmacist prescribers) in improving care in those with T2D and CVRD.

Conclusions

The addition of ethnicity as a criterion to the SAC for SGLT2i and GLP1RA appears to have increased access for Māori and Pacific peoples, but more work is urgently required to eliminate longstanding inequities in CVRD for Māori and Pacific peoples with T2D. We believe PHARMAC should strongly consider adding ethnicity criteria in all medications accessed through special authority.

COMPETING INTERESTS
Nil

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Vaping in Aotearoa New Zealand teens remains problematic: stronger regulations and education warranted

Jonathan Cox, Ben Wamamili, Philip Pattemore

E-cigarette use (vaping) by Aotearoa New Zealand youth continues to trend upwards. Vapes are promoted in Aotearoa New Zealand as a less harmful source of nicotine for current smokers who have unsucessfully attempted to quit. However, non-smokers face increased risks if they begin to vape. Surveys of young people show many vape on a daily or "regular" (at least monthly) basis, many of whom had not previously smoked. The 2022 ASH Year 10 Snapshot Survey shows that 10.2% of respondents vaped daily—a 1.1% increase compared to 2021.[1,2] The survey also showed an increase in rangatahi Māori daily vaping, from 5.9% in 2019 to 21.7% in 2022 (25% for Māori girls). Never-smokers continue to take up vaping, 4.3% having reported daily use compared to 3.1% in 2021. The 2021 ARFNZ/SPANZ vaping in NZ youth survey found that youth who vaped were overall vaping more frequently than they had a year before, and with higher nicotine concentrations.[3] Many respondents reported feeling addicted to their vapes, and thought vaping affected their health. Thus, youth vaping in Aotearoa New Zealand remains a significant public health issue. We suggest that stronger regulations on vaping products supported by knowledge-based interventions with tamariki and whānau are important to reduce the likelihood of never-vapers taking up vaping and encouraging current youth users to quit.

Stronger regulations on vaping products are necessary to reduce youth vaping in Aotearoa New Zealand. Current regulations prevent retailers from selling to minors, restrict vape flavours to tobacco/menthol/mint, and prohibit the advertisement of vapes similar to the way other tobacco products are controlled.[4] Specialist vape retailers remain exempt from some of these restrictions.[5] A recent study surveying teenagers and parents of children attending Christchurch Hospital shows that teenagers are accessing vapes primarily from friends and whānau members.[6] Furthermore, the majority of vaping teenagers stated their favourite vape flavours are fruit-based. This means that teenagers are bypassing regulations and age-restrictions through friends/whānau who can buy more diverse and appealing vape flavours through specialist vape stores or via online suppliers. The recent December 2022 legislation changes and the proposal on restriction of flavour names are important, but on their own may not be a sufficient barrier to youth accessing vapes. Areas that need to be addressed include the financial barrier to youth purchase, plain packaging, and phasing out cheap disposable vapes that are marketed and attractive to youth, as indicated by a rapid rise in use by young people in the UK.[7] Vapes are highly addictive products that are marketed as a consumer product—they require sound regulation to assist smokers without attracting non-smokers, particularly youth.

In addition to stronger regulations, it is important to educate the public that vapes are not a safe recreational product for tamariki and non-smokers. A variety of education strategies targeted at tamariki and whānau are needed to address widespread misunderstanding of vape safety. Friends and whānau are a significant way to bypass regulation and access vapes; thus, education about vaping for teenagers and adults should be emphasised. Education through media and schools is unlikely to change behaviour of regular vapers, but it may influence those curious to explore what they think is a safe recreational product. While teenagers have ready online access to information, there is doubt as to the quality of this information. A study in the USA reported that students sought information about vaping from Google, where searches can be dominated by vape marketers (85% of YouTube videos on vaping).[8] Locally, the Christchurch Hospital study reported that teenagers get information about vaping from friends and social media.[6] Thus, evidence-based education is needed. Chaplin et al. showed that in-person evidence-based education successfully improved American high school

students' knowledge of the risks of vaping.[9] In Christchurch, we are currently investigating whether delivering educational sessions to high school students influences knowledge and attitudes related to vaping. Other educational alternatives deserve exploration. A recent systematic review of interventions for adolescent substance use found that interventions addressing family function significantly reduced smoking behaviours in adolescents.[10] Mass media campaigns utilising personal testimonials were also effective. The recent Protect Your Breath campaign is one such initiative—its impact remains to be seen. Education can work in concert with regulations to help people understand the rationale for restrictions, and to provide credible information, which helps them inform choices.

Increasing e-cigarette use by youth in Aotearoa New Zealand means vapes are being utilised by the wrong population for the wrong purpose—this poses a significant public health problem. The regulations applying to e-cigarette marketing, flavours, and accessibility are necessary and require improvement, as well as supporting measures. One such measure is to continue researching and applying quality education about vaping for tamariki, parents, and wider whānau. Stronger regulations supplemented by education are important to prevent the development of a new generation of nicotine addiction.

COMPETING INTERESTS:
Nil.

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Prehabilitation for patients with cancer in Aotearoa New Zealand

Hanna van Waart, Marta Seretny

Cancer is the leading cause of death in Aotearoa New Zealand.[1] New Zealand has the second-highest age-standardised cancer incidence rate in the world (422.9 per 100,000 people). As a result, most people in Aotearoa New Zealand will encounter a cancer diagnosis within their lifetime, either directly or through whānau.[2] Māori, who make up 16% of the Aotearoa New Zealand population, have a disproportionately high cancer related mortality.[3,4]

Historically, rest and outright inactivity were recommended for patients with cancer. However, over the last two decades research has highlighted the benefits of physical activity during the cancer continuum, so much so that the American College of Sports Medicine is running an 'Exercise Is Medicine' initiative.[5] This cancer continuum is divided into four phases: 1) post-diagnosis to first treatment, 2) active treatment with chemotherapy, radiotherapy, hormonal, and/or immunotherapy, 3) survivorship, after cessation of treatment, and 4) the palliative phase. To date, most rehabilitation related studies have focused on the phases of active treatment and/or cancer survivorship. These have shown that physical activity can mitigate, or even prevent, the short and long-term side effects patients experience due to cancer and its treatment.[6] Exercise during adjuvant chemotherapy is associated with improved chemotherapy completion rates.[7,8] This, in turn, can influence disease free and overall survival.[9]

Far less research has been done into the initial phase of the cancer continuum before surgery, which is dubbed prehabilitation. Prehabilitation in its simplest form is treatment that prepares a patient for an upcoming physiological stress.[10] As a concept, prehabilitation is not new. It is an established part of Enhanced Recovery after Surgery (ERAS) protocols that are currently operating in Aotearoa New Zealand hospitals. It can encompass exercise (strength and cardiovascular), nutrition optimisation, smoking cessation, and stress reduction interventions.[11] Prehabilitation in cancer can have multiple goals: 1) maintaining pre-operative baseline measurements of function, instead of having a degraded 'baseline' after treatment (surgery, and/or adjuvant treatment), 2) improving a pre-existing health problem to better prepare for cancer surgery and/or treatment, and/or 3) improving overall functioning, including psychological health and resilience, to better withstand upcoming treatments.

Prehabilitation programmes for patients with cancer have been shown to be safe and feasible even in a very short interval between diagnosis and treatment.[12,13] Potential benefits include improved physical function, quality of life, and psychological health.[14–16] These improvements can in turn influence length of hospital stay and reduce post-surgical complications.[16] Exercise may even influence tumorgenicity directly via molecular pathways.[17]

To date, research into prehabilitation in cancer has been heterogenous in its focus. Small sample sizes across various cancer populations and setting and modes of prehabilitation delivery show benefits, but are incongruous in their generalisability.[18,19] Little research has been done on prehabilitation in Aotearoa New Zealand. Patient engagement with prescriptive generalised prehabilitation interventions is mixed.[20] It is likely that benefits of prehabilitation are optimised by programmes being tailored to the needs of specific communities.

Current research

To address these issues, we are running a study in Tāmaki Makaurau Auckland to gain insight into the needs of patients with breast cancer in the period between diagnosis and surgery. This qualitative study aims to compare patients' needs to the perception of prehabilitation held by healthcare providers. In doing so, we hope to understand the relationships and differences in existing narratives.

In this ongoing work, patients who have completed their treatment are invited to focus groups to reflect on what kind of supportive care, if any, they wanted during the period between diagnosis and surgery. The study has an *a priori* focus on Māori patients with separate hui run for

patients and whānau identifying as Māori. Semi-structured interviews with health care providers—oncologists, surgeons, anaesthetists, nurse specialists, and physiotherapists—are underway to gain insight into their perception of prehabilitation for patients with cancer. A similar study with patients who have sarcoma is about to start.

Ultimately, identification of patients' needs is the first step in our wider research programme, which will include participatory development and co-design of prehabilitation interventions.[21,22] In the coming year, patients, researchers and clinical team members will co-design a prehabilitation intervention that can be implemented and evaluated in the clinical setting. The hope is that this co-design process will lead to tailored, and thereby more effective, prehabilitation interventions in Tāmaki Makaurau.[22]

Special interest group

We have started a special interest group 'Supportive care for people with cancer' within the New Zealand Society for Oncology, in partnership with Te Aka Mātauranga Matepukupuku (Centre for Cancer Research, Waipapa Taumata Rau University of Auckland). Interested researchers from across Aotearoa are welcome to contact us for nationwide collaborations (SIGSupportiveCancerCare@auckland.ac.nz).

COMPETING INTERESTS
Nil.

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The Spahlinger Treatment of Tuberculosis

NZMJ, 1923

By Ian Macintyre, M.D., T.D.D. (Wales), Christchurch

At the end of January, 1922, I spent several days with *Mons. Henri Spahlinger* at Geneva. He went to no end of trouble in explaining to me the general lines on which he manufactures his serum and vaccine and, more especially, the clinical results he has obtained up to the present.

The following is a brief description of the preparation of the serum:

ANTITOXIC SERUM.

FIRST YEAR.

The passage of various strains of tubercle bacilli through guinea pigs to increase their virulence. Those usually obtained from a case of phthisis are not sufficiently virulent to cause the production of much toxin "in vitro."

The tubercle bacillus, according to *Spahlinger*, gives off many different toxins with correspondingly different results on the patient, but strains can be isolated that excrete one predominant toxin. For example, one causes caseation, another pyrexia and so on. They produce all the other toxins as well perhaps, but this special one is greatly in excess of the rest. From some strains he was unable to obtain any toxins at all.

SECOND YEAR.

This is spent in encouraging the bacillus to give forth its toxin "in vitro". *Spahlinger* maintains that the toxin is in many cases a defensive mechanism on the part of the bacillus, and not an offensive; consequently, unless the bacillus is worried and forced to for its existence, it is too lazy to give out toxin. There is nutriment in abundance "in vitro," and no attacking forces such as the body provides, so no toxin appears.

The successful application of these methods of irritation is most difficult of accomplishment, for it takes very little to hinder or completely stop the production of toxin; *e.g.*, white light or a different reaction of the glass. The actual details are claimed as the secrets of *Spahlinger's* success and have not been disclosed. One method I believe is to suddenly raise the temperature of the medium on which the bacillus is growing for two or more cultures of the day. Another is to expose it to red light.

THIRD YEAR.

He extracts the toxin from the culture medium.

FOURTH YEAR.

He injects the toxins into horses, giving rise to the corresponding antitoxin. The horses are always black as they give the biggest yield of the serum.

Very small doses of the special toxin are given for four months; then one month rest and then much larger doses up to perhaps 300ccs. at one injection. Now he takes the serum and tests it; if there is a sufficient strength of antibodies he bleeds the horse and may get 12 litres. Now one month rest, and then "pumps up" the horse again, but this time much more quickly, and he starts from much larger doses. This is done two, three or four times, but not more than four.

ANTIBACETERIAL SERUM.

The horse is vaccinated in exactly the same way as is done in the case of human beings to be described. It is then, with small amounts gradually increased, injected with living bacilli. This could only be done if the horse had been made highly resistant by vaccination. Thus is produced an antibody in the horse which is strongly antebactericidal to the bacillus itself.

COMPLETE SERUM.

This consists of 28 different antibodies—12 antiectotoxins, 7 antiendotoxins, 3 antibacterialysins, the remaining six being made from organism other than the tubercle bacillus which give rise to the so-called mixed infection.

At present *Spahlinger* has no "complete serum"

so is compelled to use the "partial serum" which he has numbered. For instance, one case may receive No. 1 for a few weeks; if no result, say, No. 5 may be tried; and if this gives nothing definite another number is used until one is found that may show an almost immediate improvement; *Spahlinger's* idea being that we have here given the corresponding antibody to the toxin most predominant in the patient's body. Once this has been neutralised, the scale is turned in the patient's favour and he is able to deal with the rest of the toxins. Instances of this phenomenon were shown by means of temperature charts. If the complete serum is given this method of trial is obviously unnecessary.

For surgical tuberculoses he uses in the "complete serum" 50 per cent. antibacteriolysins, and 50 per cent. Antitoxins—of the latter 20 per cent. are antiectotoxins and 80 per cent. are antiendo-toxins.

For pulmonary tuberculosis one-third antiendotoxins and two-thirds antiectotoxins; no antibacteriolysins.

As to the type of the bacillus—surgical—50 per cent. human, 50 per cent. bovine. Pulmonary—100 per cent. human.

The aim in serum treatment is progressive disintoxication of the patient by passive immunization. The injections are made intramuscularly or hypodermically according tot eh gravity of the disease and resistance of the patient. It may be several times a day up to once or twice weekly.

In abdominal tuberculosis it may be advisable to give the serum by mouth as well, and in some cases of surgical tuberculosis to inject it directly into the foci.

The length of treatment with serum varies considerably, but averages from three to six months. From the nature of the preceeding remarks it will be gathered that the serum is of more use in the in the advanced case, or, rather, that showing signs of marked intoxication. This passive immunity is short-lived and the disease is liable to recur if the serum course is not followed by a series of vaccine injections: this being a process of active immunization. This latter is also applicable alone without the serum to the afebrile cases and those predisposed to the disease.

VACCINE.

The bacillus is broken up by physico-chemical means into several component parts such as lecithin, fatty acid, albuminoid, etc. These various elements are used as antigens and injected separately into the patient to produce a corresponding series of immunity. These parts are numbered 1, 2, 3, etc. No. 1 is injected for, say, two or three weeks; then No. 1 and 2 for a similar period; then No. 1, 2, 3, and so on, until a complete series is given, when the patient receives the complete dead bacillus.

It is essential that great care be taken in the preparation of these different antigens, for any alteration in their specificity renders them less efficacious. A corresponding antibody is formed to the altered antigen and not to the original one. For instance *Spahlinger* does not believe in *Koch's* old tuberculin, because the bacillus is killed by heat. This must alter the specificity, and in consequence the antibody formed in response to it. *Spahlinger* uses light to kill the bacillus instead of heat.

What *Spahlinger* calls a ferment is given along with the vaccine sometimes. It really consists of a partial serum and therefore contains antibodies; it is supposed to facilitate immunization and avoids undesirable effects. The vaccine takes about six months to make and the course of treatment about six months also. Both the vaccine and the serum lose one-third of their efficacy after two or three years, and should not be used.

Spahlinger attaches great importance to vaccine treatment as it is more in the nature of a preventive than a curative process.

CLINICAL RESULTS.

Spahlinger showed me numerous cases embodying all types of tuberculosis which have been treated with his serum or vaccine or both. Many had tried various other methods of treatment previously with little permanent benefit, but they improved under his care.

I have facsimiles of the reports of some of these cases made by various doctors at the beginning, during, and at the end of treatment which has been arried out mainly in Geneva under *Spahlinger*, or at Montana under Dr. *Stephanie*. It has also been used in Paris and London.

In Geneva *Spahlinger* has been treating patients for many years. He was originally a lawyer by profession, but in about 1910 he took up experimental bacteriology and turned his attention chiefly to the tubercle bacillus.

His patients have come from many parts of the globe, though the majority have been residents of Geneva. Very few, if any, whatever their social status, lived in really good hygienic surroundings as far as I could gather. Geneva has by no means a good

climate for tuberculosis. The visitors stay in hotels and come to Spahlinger for their injections, otherwise no supervision is made. They arise and go to bed, eat and drink, and exercise or rest just as they please, and, from my experience of patients in general in Switzerland, would not over-indulge in fresh air. I mention these points, for it cannot be said that these patients, like those at Montana, were living under sanatorium conditions.

I was permitted to question and examine a number of them and found the majority showed very few, if any signs of active tuberculosis. All cases were definitely tuberculosis, as bacilli had been found in the sputum. Some were old chronic cases, but by no means all, for, judging by the physical signs and history, many must have been acutely toxic on arrival in Geneva.

Spahlinger does not claim that the serum will cure every case and he wishes to impress this fact on the medical profession. He seldom has a failure with surgical tuberculosis, but it not always successful with pulmonary disease. He is very much afraid of articles in the daily press, as he feels, and rightly so, that such writings, for which he was in now way responsible, have in the past done him an enormous amount of harm in the eyes of the medical profession.

For my own part I must admit that I went to Geneva a confirmed sceptic, but came away feeling that, if *Spahlinger* has not actually found a cure for tuberculosis, he is at least working on the right lines, and has made a distinct advance towards the goal for which we are all aiming. Before one can speak more definitely on the subject the serum and vaccine must be made available in sufficient quantities so that others may give them a trial. To enable this to be done *Spahlinger* must be relieved of his financial difficulties, and it would be a wise expenditure of private or public money devote to this end. I believe the British Red Cross Society have advanced him a sum of money to assist him to produce the serum he has at present under manufacture. It apparently involves the outlay of a large amount of time and money, and as *Spahlinger* has never up to the present made any charge for treatment, either to those receiving it at his hands or from others, he has been at considerable financial loss.

His laboratory, which, by the way, is duplicated in every detail in case of fire, is most elaborately fitted up and some of the contrivances he has there are most ingenious.

In common with the great majority of visitors to *Spahlinger* I am perfectly satisfied that he is absolutely genuine and honestly believes that he has a remedy that is going to rid the world of a terrible scourge.

CRITICISM.

Critisicism of *Spahlinger* is based chiefly on his failure to publish the details of his treatment, and allow competent clinicians and bacteriologists to judge its worth. He has been accused of endeavouring to commercialise his discoveries in that he is asking what seem to be large sums of money from various countries for the rights to use and manufacture his serum and vaccine. He is by many called a quack, for he is not a medical man. It is stated that Spahlinger has no satisfactory method of standardization of his serum; that he has given no satisfactory proof of the existence of toxins in the culture medium, nor antibodies in the serum, and that many of his ideas on baceteriology are quite unsound. These, and other objections of a similar nature, may be justified, for I am not sufficiently versed in bacteriology to express an opinion. But I do hold that he is not bound, morally or otherwise, to disclose his secrets, and that he is quite within his rights in endeavouring to recoup himself for all his labours and expense in the past.

The treatment has now obtained a world-wide reputation, and any publication of the details of manufacture without protection would be immediately followed by a perfect deluge of preparation by proprietary firms, stating that they had been made in accordance with *Spahlinger's* directions. It is obvious that the serum cannot be made in a day and some of the technical details, according to *Spahlinger*, need great care and attention, otherwise the resulting product will be valueless. He is afraid that these firms, in their anxiety to put it on the market, would bring discredit on his treatment before he himself had established its value.

Again, *Spahlinger* has spent anything up to £100, 000 of his own money on the equipment and working of his laboratories. He is now almost penniless and unable to carry on without assistance from the British Red Cross Society.

Can we expect any man to make such a sacrifice and offer him no other recompense than that of handing down his name to posterity as the man who discovered a cure for tuberculosis?

What does it matter to us in the meantime how this serum is made whether its contetns are all that *Spahlinger* says they are, and whether *Spahlinger* is

right or wrong in his desire to make us pay for the use of it? To my mind the questions resolves itself into this—Is *Spahlinger* getting more successful results by his method of treating tuberculosis than have been obtained in the past? If so, and it is the opinion of the majority of those who have investigated his claims, that they are little, if at all, exaggerated, then is it not our duty to obtain serum and vaccine for the benefit of our tuberculous population?

It is always a difficult matter to assess the therapeutic value of a remedy and especially is this the case in a chronic disease like tuberculosis. So many "cures" have been announced in the past, and still tuberculosis seems to be as prevalent as ever. It is to be regretted that *Spahlinger* has given no statistical results of his treatment, though perhaps their value is not as great as one might at first imagine.

My purpose in writing this article has been to try and interest the medical profession in *Spahlinger's* treatment and to put before them the true facts of the position, for the extravagant statements made at times in the daily press are often untrue and certainly misleading.

Since writing the above I have heard that *Spahlinger* has collected statistics of his cases, but I have none by me at present. I have one or two patients on the partial serum and the results, so far, are by no means discouraging, but it would not be fair to pass any judgment on the serum until I have tried the complete serum, which I hope to obtain in the near future. If I can give any further information to anyone interested I shall be only too pleased to do so.

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An observational study of the incidence and treatment of postpartum anaemia in Aotearoa, New Zealand

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BACKGROUND

The incidence of postpartum anaemia (PPA) in Aotearoa, New Zealand is unknown. Intravenous (IV) iron is a recent alternative to red blood cell transfusion (RBC-T) for treatment of moderate-to-severe PPA; however, the extent of its use is unknown. Our aim was to report on the incidence and management of PPA.

METHODS

A retrospective observational study of PPA (haemoglobin (Hb) <100g/L) at tertiary hospitals in three regions across Aotearoa (Counties Manukau, Waikato and Canterbury) between 1 July 2019to 31 December 2019. Case note review was undertaken with Hb <90g/L. Management was compared to local and national guidelines.

RESULTS

Eight thousand, eight-hundred and forty-nine women gave birth during the study period: 4,076 (46%) had postpartum Hb testing and 1,544 (38%) had PPA. Of those tested, and after adjusting for deprivation and region, European women had lower adjusted odds ratios compared to Māori for being identified as having PPA (0.46, 95% confidence interval 0.37–0.57, $p<0.01$). Of 681 women with Hb <90g/L, 278 (41%) received IV-iron only, 66 (10%) RBC-T only and 155 (23%) both. Management varied by severity of PPA (table). Of those receiving RBC-T, 40/221 (18%) were actively bleeding. Māori (92/138, 67%) and Pacific (127/188, 68%) women with Hb <90g/L had the highest incidence of IV-iron use. No guidelines provided recommendations for haemodynamically stable women without active bleeding.

	Moderate PPA (Hb 80–89 g/L) 429 (100)	Moderate to severe PPA (Hb 70–79 g/L) 187 (100)	Severe PPA (Hb <70g/L) 65 (100)	Total case reviews n (%) n=681
RBC-T	21 (5)	29 (16)	16 (25)	66 (10)
IV iron	203 (47)	69 (37)	6 (9)	278 (41)
RBC-T and IV iron	41 (10)	72 (38)	42 (64)	155 (23)
No RBC-T or IV iron	164 (38)	17 (9)	1 (2)	182 (26)

CONCLUSIONS

The incidence and management of PPA differs by ethnicity but fewer than half of women had Hb-testing, making precise determination of incidence impossible. The majority of women with Hb <90g/L received IV-iron, with or without RBC-T. There is a lack of guidelines for clinically stable women. Further research exploring the reasons for differences in PPA by ethnicity is required, as well as evidence on the comparative effectiveness of IV-iron and RBC-T for moderate-to-severe PPA to guide clinical practice and support more consistent care across Aotearoa.

Neonatal gastric perforation, is it preventable?

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AIM

Neonatal gastric perforation (NGP) is a rare surgical emergency needing urgent surgical intervention. This study aimed to find any preventable cause of NGP.

METHODS

We retrospectively reviewed clinical notes, charts, and operative findings of all neonates with gastric perforation for 22 years. The demography, gestational age at birth, age of perforation, potential risk factors during Neonatal Intensive Care Unit (NICU) stay, intraoperative findings, surgical incision site and outcomes were analysed.

RESULTS

Eight babies with NGPs were identified in NICU (three babies—Māori, three—Pākehā). The gestational age ranged from 24–35 (mean 28.4±3.4 weeks), and the birth weight was 700g to 3,030g (mean 1,402g). Seven had respiratory distress needing CPAP (n=6) or intubation (n=1). One baby on room air had <1cm perforation in the posterior gastric wall caused by the nasogastric tube (NGT). The intubated baby had a 1.5cm perforation due to necrotising enterocolitis (NEC) involving the posterior gastric wall. The remaining six babies had the perforation at the greater curvature (GC). The perforations longer than 2cm were associated with C-PAP ($p<0.05$). Six had left upper quadrant surgical incisions due to pre-operative suspicion, and two had right-sided incisions requiring an extension of the incision. The NGP mortality is 1 out of 8 (12.5%).

CONCLUSION

C-PAP is the leading cause of gastric perforation in low birth weight and premature babies. Careful radiological and clinical assessment for a firm pre-operative diagnosis leads to appropriate surgical incision. NG tube on drainage during CPAP may prevent pneumatic rupture.

GP prescription patterns for atopic eczema in children before and after teledermatology advice

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BACKGROUND

Despite comprehensive guidelines, atopic eczema in children remains widely undertreated. Access to dermatologists is limited and the majority of children are treated in primary care. We reviewed whether tailored dermatologist advice, offered via telemedicine (in the form of a written non-contact first specialist appointment (ncFSA) was able to influence general practitioner (GP) prescribing patterns.

OBJECTIVE

To assess whether advice provided to GPs through ncFSA for paediatric atopic eczema influences actual prescribing, and whether this adheres to current best practice.

METHODS

A retrospective review of data was performed comparing dermatologist prescribing advice in the ncFSA to actual GP prescribing in the 6 months following referral. Analysis was performed to assess equity for different socio-economic positions, rurality, and Māori patients.

RESULTS

One hundred and sixty-two patients were included in the study including 83 males and 79 females with an average age of 62 months. Prior to ncFSA, 29 (17.9%) of patients were receiving an appropriate topical corticosteroid for affected eczema areas, which increased to 97 (59.9%) post ncFSA. The number of children receiving an appropriate moisturiser also increased from 47 (29%) to 88 (54.3%). Antimicrobial, combination corticosteroid with antimicrobial, sedating antihistamine and antibiotic use all decreased post ncFSA. Systemic corticosteroid use was similar before and after ncFSA.

The quantity/quality of the medications that patients received did not seem to be affected by ethnicity, with the exception of systemic corticosteroids and antibiotics, which Māori patients were more likely to receive. Rurality was positively associated with amount of topical corticosteroid and moisturiser received, as was a higher level of socio-economic deprivation. Overall 58.2% of products recommended by dermatology were dispensed, and 50.8% of dispensed products had been recommended in the ncFSA.

CONCLUSION

While there were positive changes seen post-ncFSA, such as more appropriate topical corticosteroids and moisturisers being prescribed, issues such as antimicrobial/combination corticosteroid use continued to persist. The lack of correlation between the medications recommended in the ncFSA and the medications prescribed, suggests a need for better communication, and education in primary care setting. In addition, perhaps other methods of deliver-

ing specialist treatment/advice to paediatric eczema patients should be explored.

Post-reduction observation of paediatric intussusception in Waikato, New Zealand

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AIM

To assess the management and outcomes in children with intussusception in the Waikato Region over 15 years.

MATERIAL AND METHODS

This is the Waikato arm of a national multi-centre retrospective study. We collected data from 1 January 2007 to 1 January 2022 on patients under 15 who underwent radiologic or surgical intervention for intussusception. In addition to demographic data, we recorded the duration of hospital stay, need for surgery and, rate of recurrence in children with intussusception, use of antibiotics. The primary outcome was the duration of stay after enema reduction. Patients with incomplete data were excluded from the RECAP platform for data collection, and statistics were done in the Tableau app.

RESULTS

Out of the 92 patients, we excluded two. Forty-seven (52 %) patients were transferred from another hospital. Sixty-six (73 %) were males, and 24 (26%) were females. Māori comprised 23% (n=26). The post-enema reduction length of stay was 25.18 hours on average. Ultrasound detected intussusception in 98% of the patients. Forty-three (48%) needed surgical intervention. Sixty-three percent (n=51) were successful with air enema. Only three (3%) patients had a recurrence, with two having it in the same admission. All of them were treated with another enema reduction. No antibiotics were given to 39 (43%) patients.

CONCLUSION

In most cases, intussusception is successful with air enema reduction, and few patients require surgical options. A management protocol with multi-departmental input has the potential to reduce unnecessary operations and decrease the time in the hospital.

The implementation of healthy homes screening in paediatric wards of Waikato Hospital, New Zealand, has the potential to improve health outcomes and reduce hospital admissions

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OBJECTIVES

There is a well-established relationship between housing conditions, health outcomes, and health equity, for tamariki (children). However, few studies have assessed how the implementation of healthy homes screening affects the rate of referral to housing support services in a health setting. The objectives of this research were to examine the relationship between poor housing conditions and paediatric hospital admissions at Waikato Hospital over a 6-year time frame. Further, healthy homes screening data from the Harti Hauora Tamariki randomised controlled trial (RCT) was compared between the usual care and intervention group in order to evaluate the rate of referrals to the local healthy homes initiative—Whare Ora.

METHODS

A coding algorithm was used to determine how many admissions (aged 0–5 years) to Waikato Hospital acute paediatric medical wards, between February 2014 and February 2020, would have been potentially avoidable due to poor housing quality.

Cross sectional analysis of data obtained in the Harti Hauora Tamariki RCT was compared between tamariki who received the Harti intervention, which included healthy homes screening, and those that received usual care. Clinical notes and the Whare Ora databases were searched to find any documentation of housing information, interventions received, and the rate of referral to Whare Ora for both groups.

RESULTS

More than 50% of paediatric medical admissions at Waikato Hospital were considered potentially avoidable due to poor quality housing. Over 65% of all tamariki Māori admissions were considered potentially avoidable. For the cohort of patients in the Harti RCT, with the use of the healthy homes screening, documentation of housing information (99%) was almost double that of usual care (53%).

The housing information gathered could be used to determine eligibility for referral to Whare Ora services. Thirty-three percent of the intervention cohort were referred to Whare Ora, with only 20% of the usual care cohort referred.

CONCLUSIONS

Poor housing conditions are a predisposing factor in more than half of paediatric medical admissions at Waikato Hospital, and they also contribute to health inequities. Implementation of the Harti Hauora intervention significantly improved housing assessment, documentation, and, more importantly, led to an increased rate of referral to the Whare Ora programme, therefore reducing the risk of further hospitalisation, GP visits and medication need. The potential health equity gains from increased referrals are significant, leading to reduced avoidable paediatric hospital admissions and readmissions and even mortality.

Ngā hua o te kōpū – improving health outcomes for wāhine māori with diabetes in pregnancy

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INTRODUCTION

Ngā Hua o te Kōpū recognises colonial impacts on Māori inequities in diabetes in pregnancy (DiP). The prevalence of DiP rise in Māori results in poor intergenerational health outcomes. This study's objective was to amplify voices of wāhine Māori to produce recommendations to the Waikato DiP service to improve Māori health outcomes.

METHODS

Utilising transformative kaupapa Māori research (KMR) methods five focus groups occurred across the Waikato region in Kirikiriroa (Hamilton), Hauraki, Rāhui Pōkeka (Huntly), Taumarunui and Tokoroa, to share wāhine Māori space, knowledge, and experience of DiP.

RESULTS

Thematic analysis identified three themes 1) impact of diabetes: the importance of time for wāhine to accept their diagnosis and activate self-management of diabetes; 2) relationships: between wāhine and clinicians, and value whānau contributions; and 3) aspirations for DiP: including three subthemes calling for options in the areas antenatal clinic, modes of communication mode and Māori-led sharing of information and education.

DISCUSSION

The themes and their associated sub-themes illustrated four kaupapa pou (pillars) that illustrate how services can meet the aspirations of wāhine Māori. Whanaungatanga (reciprocal relationships), tino rangatiratanga (self-determination), manaakitanga (centralising Māori with DiP voices), and the Crown's obligation to uphold te Tiriti obligations.

CONCLUSION

Ngā Hua o te Kōpū highlighted themes explaining wāhine experience of DiP care which extend to four pou outlining wāhine Māori-informed initiatives for DiP service changes. While it is not possible to undo the impacts of colonisation on Māori, this research project reflects and learns from the past to make progress for the future. A future where Māori navigate their own journey for DiP care (tino rangatiratanga) with support of the Crown (te Tiriti obligations), utilising reciprocal relationships (whanaungatanga) within a DiP service that delivers respectful, generous, care for others (manaakitanga).

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Acute calcium pyrophosphate crystal arthritis is associated with an increased rate of hip and knee joint surgery

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BACKGROUND

Acute calcium pyrophosphate (CPP) crystal arthritis is a distinct manifestation of calcium pyrophosphate crystal deposition (CPPD). No studies have specifically examined whether acute CPP crystal arthritis is associated with progressive structural joint damage. This retrospective cohort study evaluated the relative rate of hip and knee joint arthroplasties as a surrogate of structural joint damage

accrual, in a population of patients with acute CPP crystal arthritis.

METHODS

Data were collected from Waikato District Health Board (WDHB) to identify a study population with clinical episodes highly characteristic of acute CPP crystal arthritis. Data on hip and knee joint arthroplasties were collected from the New Zealand Orthopaedic Association's (NZOA) Joint Registry. The rate of arthroplasties in the study group were compared to the age-ethnicity matched New Zealand population. Additional analysis was performed based on age, obesity (BMI) and ethnicity.

RESULTS

The study population included 99 patients, 63 were male and the median age was 77 years (interquartile range [IQR] 71–82). The obesity rate was 36% with a median BMI of 28.4kg/m^2 (IQR 25.8–32.2), comparable to the New Zealand population. The standardised surgical rate ratio in the study group versus the age matched New Zealand population was 2.54 (95% CI: 1.39–4.27).

CONCLUSION

Our study identified a significant increase in the rate of hip and knee joint arthroplasties in patients with episodes of acute CPP crystal arthritis. This suggests CPP crystal arthritis may be a chronic condition, leading to progressive structural joint damage.

Comparison of three delirium screening tools for detecting pacu delirium

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AIM

Early signs of delirium are commonly observed in the Post Anaesthesia Care Unit (PACU); however, delirium screening tools validated in the PACU setting are lacking. We compared three frequently used tests to identify a sensitive test to screen for PACU delirium.

METHODS

This was a *post hoc* secondary analysis of data from the Alpha Max study, which involved 200 patients aged over 65 scheduled for elective surgery under general anaesthesia lasting more than 2 hours. Patients were assessed for delirium 30 minutes following arrival in the PACU, if they were adequately arousable. The tests performed for delirium screening were 3D-CAM, CAM-ICU, and NuDESC, each of these multidomain instruments were compared to one another to determine the most appropriate test to detect delirium in the PACU.

RESULTS

Our study's incidence of PACU delirium was 35% (3D-CAM) and individual cognitive domains were affected differently. CAM-ICU (27%) and NuDESC (52.8%) detected fewer PACU delirium cases than 3D-CAM. CAM-ICU had a sensitivity of 0.27 (with 95% CI 0.17–0.39), while NuDesc had a sensitivity of 0.48 (with 95% CI 0.36–0.61). The specificity of both tests was 1 (with 95% CI 0.97–1.0) and 0.97 (with 95% CI 0.93–0.99), respectively.

CONCLUSION

While highly specific, neither CAM-ICU nor NuDESC are adequately sensitive to identify delirium in the PACU. The instruments of delirium screening used in our study assessed the same cognitive domains, however the complexity of the assessments varied, rendering specific tests less challenging than others.

ABBREVIATIONS

3D-CAM = 3-minute Diagnostic Confusion Assessment Method; CAM-ICU = Confusion Assessment Method ICU; NuDesc = Nursing Delirium Screening Scale.

Post-operative outcomes of intracapsular tonsillectomy with coblation: a systematic review and meta-analysis

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AIM

In the post-operative course following tonsillectomy, haemorrhage from the tonsillar bed can be a significant and serious complication. With consideration of long-term symptom alleviation, intracapsular tonsillectomy with coblation is considered to minimise short term post-operative complications. This systematic review and meta-analysis seek to analyse available data on short term complications and long-term outcomes from intracapsular tonsillectomy with coblation focusing primarily on post-tonsillectomy bleeding rates.

METHODS

A pre-piloted search strategy was used to search MEDLINE, Embase and the Cochrane library.

Studies published in the English language between December 2002 and July 2022 with primary data on post-tonsillectomy haemorrhage with intracapsular tonsillectomy with coblation were identified from the search. Studies were excluded if they were not full text, lacked primary data or did not report rates of post-tonsillectomy haemorrhage. Studies were screened by title, abstract and full text by two independent reviewers. Data were extracted by a prepiloted form and results summated and analysed.

RESULTS

Data from 9,821 patients across 14 studies were used in quantitative analysis. The overall proportion of total haemorrhage was 1.0% (CI 0.5%–1.6%). Primary and secondary haemorrhage proportions were 0.1% (CI 0.0–0.1%) and 0.8% (0.2%–1.4%) respectively. The proportion requiring further tonsil surgery was 1.4% (CI 0.6–2.2%) though with high heterogeneity.

CONCLUSIONS

Post-tonsillectomy haemorrhage rates in this systematic review and meta-analysis demonstrate that intracapsular tonsillectomy with coblation is safe from the perspective of post-tonsillectomy bleeding. Data regarding long-term tonsil regrowth and need for re-operation was encouraging of the efficacy of the technique, though demonstrated variability which limited the strength of analysis.

Shared decision making for older patients with colorectal cancer: a novel approach

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AIM

Colorectal cancer (CRC) is common in older patients, and medical comorbidity makes decision making around major surgery complex. The traditional approach relies on the surgeon to identify high-risk patients then work-up and/or refer appropriately. We describe early experience of a novel patient-centred shared decision making (SDM) pathway in our tertiary referral centre for older patients with colorectal cancer in which surgical resection is being considered. The pathway goals are to identify high-risk surgical candidates, stratify risk and enable SDM when moderate or high-risk surgery is deemed the gold standard treatment by the colorectal multi-disciplinary meeting (MDM).

METHODS/INTERVENTIONS

From 1 January to 31 December 2020, all patients diagnosed with CRC over 70 years of age were directed to be screened for frailty using the G8 frailty score prior to the colorectal MDM at Waikato Hospital. A prospective database was maintained of all patients with CRC over the age of 70 years discussed at the CRC MDM. Additional retrospective data collection was performed for follow-up data. An anaesthetist and a geriatrician routinely attended the MDM and the first specialist appointment (FSA) in the colorectal surgery clinic to facilitate a SDM approach in a single appointment. Patients being considered for CRC surgery with a G8 frailty score <14 or with multiple comorbidities underwent a holistic assessment by an anaesthetist, geriatrician and colorectal surgeon. Outcomes assessed included frailty scores, mortality, deviation from MDM recommendation, complications and length of stay (LOS).

RESULTS/OUTCOMES

One hundred and seventy-seven patients over 70 years (median 78, range 70–94) were discussed in the MDM during the study period. Median follow-up was 12.3 months. One hundred and six had a G8 score completed, median G8 was 13. Forty-three out of one hundred and seventyt-seven patients were seen in the SDM clinic (31 with anaesthetist and 42 with geriatrician). Surgery was recommended in MDM (prior to FSA) in 39/43 (90.7%) of SDM clinic patients, following clinic review 17/39 (43.6%) did not have surgery. All 17 of these patients were alive at 3 months, but seven died during follow-up (median 6 months). Twenty-two patients had surgery planned to follow the SDM clinic. For those that did undergo surgery all were alive at 3 months, but two died during follow-up, after four and 14 months. Median LOS was 7 days for all SDM patients; two patients returned to theatre in less than 30 days. Seventy out of one hundred and seventy-seven patients were seen by a colorectal surgeon separate to the SDM, 66 for whom surgery was recommended by the MDM. Fifty-seven out of sixty-six patients underwent surgery, of which 55/57 (96.5%) were alive at 3-month follow-up and seven died during follow-up at a median of 4 months. Median LOS was 6 days for non-SDM patients; six patients returned to theatre in less than 30 days.

CONCLUSION/DISCUSSION

Almost half of patients seen in the SDM clinic did not have surgery despite this being the MDM recom-

mendation. Patients from the SDM clinic who did not have surgery had a high early mortality rate, unlikely due to cancer progression. The SDM model described may improve decision making for older patients with CRC by tailoring risk assessment and discussion of treatment options with all key stakeholders in an efficient and timely fashion. Further work is being done to elucidate differences in outcomes for SDM clinic patients as well as obtaining the results of longer follow-up.

Outcomes following cytoreductive surgery and hyperthermic intraperitoneal chemotherapy: 12 years of experience in a national referral centre in Aotearoa New Zealand

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INTRODUCTION

Cytoreductive surgery (CRS) and hyperthermic intraperitoneal chemotherapy (HIPEC) is the standard of care for selected cases of peritoneal malignancy.

AIMS

We aimed to evaluate the outcomes following CRS and HIPEC at Waikato District Health Board and Braemar Hospital, which have provided treatment for patients from all regions in New Zealand since 2008.

METHODS

Retrospective review of a prospectively maintained database of all patients undergoing CRS and HIPEC from 1 January 2008 to 1 November 2020 at Waikato District Health Board and Braemar Hospital. We analysed operative outcomes, perioperative morbidity and mortality, and long-term survival.

RESULTS

Two hundred and forty procedures were performed for 221 patients with a median age of 55 years. One hundred and seventy-two patients were European, 29 were Māori, and 14 were Pasifika. There was considerable variation in the number of referrals from different regions of New Zealand. The median PCI was 16. One hundred and ninety-six cases (81.7%) received complete cytoreduction (CC0/1), 33 (13.8%) underwent palliative debulking, and 11 (4.6%) had an abandoned procedure. HIPEC was administered to 100% of CC0/1 cases and 6.8% of CC2/3 cases. Fifty-six cases (23.3%) had at least one major complication (Clavien–Dindo grade 3 or 4). There were two mortalities (0.8%) within 30 days. There were 152 low-grade appendiceal mucinous neoplasm (LAMN), 20 high-grade appendiceal mucinous neoplasm (HAMN), 29 appendiceal cancers, 39 colorectal cancers, eight ovarian cancers, and six peritoneal mesothelioma. Five-year overall survival (OS) for LAMN, HAMN, appendiceal cancer, and colorectal cancer were 71.5%, 49.5%, 20.8%, and 40.4%, respectively.

CONCLUSION

We found favourable short- and long-term outcomes following CRS and HIPEC in New Zealand comparable to the international literature.