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Calum Fisher, Oliver Sutcliffe, Peter Coghlan, Andrew McCombie, Laura Joyce

New Zealand emergency departments continue to be utilised for dental conditions such as toothache or dental abscesses. Young adults, Māori, Pacific Peoples and those living in high deprivation areas are over-represented. These patients receive non-optimal care in the emergency department as they are ill-equipped and staffed by non-dentally trained health professionals. Treating these dental conditions in emergency departments may contribute to increased healthcare costs, overcrowding, unnecessary radiation exposure and inappropriate prescribing of opioids and antibiotics.

How young people in Aotearoa perceive vaping and the associated oral health risks

Hillary Hang, Rosie Dobson, Judith McCool

This study aimed to explore how young people in Aotearoa New Zealand perceive risks of vaping, including the risks to oral health. An online survey of 237 young people aged 16–24 years was undertaken. Although most participants understood that vaping posed risks to their general health, they reported lower levels of perceived risk of vaping on oral health. Participants who were current vapers held significantly lower perceptions of both the addictiveness and harms associated with vaping. Participants reported that oral health professionals seldom asked them about their vaping status. Most participants were open to discussing with oral health professionals about the effects of vaping on their oral health, suggesting that they would be less likely to vape if they knew it was bad for their oral health.

Non-attendance at diabetic retinal screening in Te Tai Tokerau, Northland, Aotearoa New Zealand

Laura E Wolpert, Christopher HJA Sadler, Andrew R Watts, David M Dalziel

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Exploring the impact of e-learning modules and webinars on health professionals' understanding of the End of Life Choice Act 2019: a secondary analysis of Manatū Hauora – Ministry of Health workforce survey

Aida Dehkhoda, Rosemary Frey, Melissa Carey, Xuepeng Jing, Jacqualine Robinson, Frederick Sundram, Nicholas R Hoeh, Susan Bull, David Menkes, Gary Cheung

This paper explores the socio-demographic factors associated with health professionals' completion of the e-learning module and attendance at the two webinars provided by the New Zealand Ministry of Health – Manatū Hauora, and whether completion of the e-learning module and webinars supported health professionals' understanding of the End of Life Choices Act 2019. This association is determined by a secondary analysis of the Ministry of Health workforce surveys conducted in July 2021. Results show that health professionals who are older, of Pākehā/European ethnicity, and work in hospice settings are more likely to complete the e-learning module, while females are more likely to attend webinars. Despite low completion and attendance rates, the study highlights the positive association between training and health professionals' overall understanding of the Act. These results emphasise the need for enhancing training programs to increase health professionals' knowledge and competence with AD.

Exploring older peoples’ attitudes and preferences around the use of their healthcare information

Cristian Gonzalez-Prieto, Daniel Wilson, Gillian Dobbie, Claudia Rivera-Rodriguez, Susan Yates, Reshmi Rai-Bala, Tara Sani, Rosie Dobson, Sarah Cullum

De-identified health data have been shown to be an important source of information for health research, but, under New Zealand law, do not require individual consent for use. In this article we present the results of an online survey carried out among people who used Te Whatu Ora Counties Manukau health services, inquiring about their knowledge of the current use of de-identified health data and their comfort levels around its use. It was found that around 80% of the respondents understood how their de-identified data were used, and between 80 and 87% felt comfortable or very comfortable with the potential use of their health data. Some concerns about privacy and confidentiality were mentioned, as well as cultural concerns about the use of data after death.

Low and intermediate risk aortic dissection detection risk score and negative D-dimer: a word of caution

Steve W F R Waqanivavalagi

Acute aortic syndrome (AAS) is a rare, vascular catastrophe with high mortality. In New Zealand, the incidence of AAS is higher than elsewhere in the world, especially for patients of Māori and Pacific Island descent. Ongoing work is being undertaken to determine whether novel rule-out strategies, such as the aortic dissection detection risk score and negative D-dimer, may be useful in excluding AAS without the requirement for advanced imaging. However, although its use has crept into the work-up of patients with suspected AAS, its use remains to be validated, especially in New Zealand.

Recurrent Takotsubo syndrome with variable echocardiographic and electrocardiographic appearances

Aleisha Easton, Andrew J Kerr, Jen-Li Looi

Patients with recurrent Takotsubo syndrome may not represent with the same echo and ECG appearances as the first episode. Clinician should also be aware that recurrent Takotsubo syndrome may occur many years later after the first episode. The variation in ECG pattern we observed between recurrent events with differing echocardiographic variants is still not fully understood and should be further investigated.

State of general practice in New Zealand

Bryan Betty, Jo Scott-Jones, Les Toop

If general practice fails then the health system fails.[1]

We are not alone in understanding the vital role general practice plays in successful health systems. Internationally, and over time, the evidence is clear.[2,3]

However, we clearly have a problem.

The system has not delivered equitable outcomes to sectors of the Aotearoa New Zealand community, especially for Māori and Pasifika communities,[4] the system is not providing population health outcomes that meet expectations[5] and the system is not providing its workforce with working conditions that are attractive or sustainable.[6]

The latest Commonwealth survey[7] showed younger general practitioners (GPs) have the highest rates of burnout. We also know that the proportion of GPs is falling in the Aotearoa New Zealand health workforce. Not nearly enough young doctors are choosing a career specialising in general practice.

The effect of this mismatch is that a growing and ageing population is being cared for by an ageing, diminishing and dispirited health workforce, large numbers of whom are contemplating relocation or retirement at or before the normal retirement age, citing stress, burnout and feeling unsupported.[6] As the population ages so does complexity of care, with Māori and Pasifika suffering higher levels of multi-morbidity at a younger age.

How do we move forwards to a sustainable, affordable health system the public trusts, which delivers high-quality equitable outcomes and satisfying working conditions?

Why is this not happening already in Aotearoa New Zealand, when we have known what success looks like for such a long time? Much as politicians find it hard to admit in public, why is it the Aotearoa New Zealand health system has moved into crisis mode over recent years?

Many of the reasons for our current situation stem from an insufficient, poorly distributed, under-valued and under-resourced workforce—one that does not reflect the ethnic and sociocultural diversity of the population it serves.

The current inadequate and worsening workforce demographics were both predictable and repeatedly predicted decades ago. The folly of Aotearoa New Zealand's historic reliance on shoring up the health workforce with overseas-trained health workers came home to roost when the pandemic closed our borders.

Investment by successive governments has failed to provide and maintain adequate facilities, nor to train the workforce needed to service rapid population growth and the associated increased demand. Now the borders are reopened, many other developed countries find themselves with the same workforce shortages and the global market for skilled health workers has become highly competitive.

For general practice, the way forward to a sustainable, equitable system involves regaining adequate staffing levels, with an interdisciplinary workforce—the makeup of which better reflects Aotearoa New Zealand society, and which has the capacity, capability and connections to deliver accessible, high-quality care in partnership both with communities and with the wider health and social care systems.

While there are encouraging examples of great teamwork throughout the country, there are many systemwide changes that will be necessary to turn the ship around and achieve this worthy goal across the motu.

The traditional model of 15-minute consultations is no longer adequate for caring for the growing number suffering multi-morbidity and associated polypharmacy, many with additional social problems linked to ageing, living alone and experiencing economic hardship.

In 2001, when the primary healthcare strategy and enrolment were first introduced, the average number of GP visits per year used for modelling the base capitation funding formula was only 2.5 per year. The model is poorly targeted to those most in need and urgently requires a major overhaul. Although there have been incremental increases over time, these do not reflect the increased costs of running a medical practice. Full-time GPs (or equivalent part-timers) now see more patients, more often and for more complex needs than when the formula was introduced 20 years ago. In the face of rising costs, this is increasingly financially unsustainable.

In addition, general practice has long been seen and used by other parts of the health system as the universal backstop, with assumed uncapped ability to mop up lack of capacity elsewhere. This is no longer possible and, consequently, emergency departments are increasingly required to manage chronic conditions or the consequences of inadequately managed long-term problems. This results in a vicious cycle of further poor management that directly impacts equitable health outcomes, as the people with the least capacity to access the system find themselves in the greatest need.

As public hospital capacity has diminished relative to increased demand, and as they have been faced with their own workforce shortages, secondary care has had to raise thresholds for referral both for first specialist appointments (FSAs) and for planned care. Similarly, waiting lists for those accepted for FSAs and subsequent care grow longer and longer. While people are waiting for hospital and specialist interventions, we know they use general practice at a higher rate, further adding to capacity pressure in the system.

The administrative burden of trying to meet inconsistent, changing and ever more restrictive referral criteria has fallen back onto general practice, as has the explicit expectation to provide additional and unfunded ongoing clinical care for those on the growing waiting lists, those whose referral has been rejected on grounds of "insufficient capacity", and those who need follow-up care after increasingly early discharge.

The increasing complexity of care and associated administrative burden, unsolicited work resulting from a lack of capacity elsewhere in the system, funding formula long since unfit for purpose and workforce shortages represent a perfect storm.

In response to this additional work and in striving to provide the best care possible for existing patients, general practices in many areas have been forced to close their books to new patients and waiting times for routine appointments in many areas have ballooned from days to weeks.[8] These are, in effect, the same rationing methods long used in planned secondary care.

As these rationing methods cannot be applied to acute and emergency care, unmeetable demand in general practice leads to longer and longer waiting times for stressed patients and staff in urgent care clinics and emergency departments. In rural areas, where there are no alternatives, urgent care has to replace capacity for routine and planned care.

As we move forward with the *Pae Ora (Healthy Futures)* legislation, focus hopefully will once again fall on the numbers and makeup of the workforce and the skills that are needed to deliver a future high-performing health system. Te Whatu Ora – Health New Zealand's recently released *Health Workforce Plan 2023/24* has six key targets that appear to be a move in the right direction—whether it turns the tide in time remains to be seen.

As the scopes of practice of both existing and new staff evolve and are (re)defined, some discomfort can be expected. The future role and best use of specialist physicians working as generalists in the community (aka GPs) could usefully be re-examined from community, practitioner and system perspectives.

The evidence of patient benefit and positive health outcomes from generalist healthcare teams providing comprehensive and continuity of care in the community is both strong and substantial.[2,3] The best use of generalist physicians should include managing the most complex medical situations.

A funding and business model that allows sufficient time for these physicians to carry out that work should be a high priority. Working with the complex will require reallocation of some of their existing workload to other team members. This will no doubt be embraced by some and resisted by others. It will also require widening the scope of postgraduate training and education programmes.

We need a framework through which high-quality sustainable general practice can deliver to all New Zealanders, and which addresses long-standing inequitable health outcomes. This is the core challenge for the government and central health agencies as we implement the *Pae Ora* legislation.

If we want to achieve more equitable health outcomes, we clearly need to do some important things differently. However, the system must also recognise, celebrate and continue to support the many innovations driven by the sector over the last 20 years.[9]

The need for cross-party accord on long-term workforce and health system planning has never been more necessary, nor, as it seems from recent pronouncements, more distant.

The Aotearoa New Zealand public and health workforce deserve better.

COMPETING INTERESTS

Nil.

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REFERENCES

1. Roland M, Everington S. Tackling the crisis in general practice. BMJ. 2016 Feb 17;352:i942. doi: 10.1136/bmj.i942.
2. Starfield B, Shi L, Macinko J. Contribution of primary care to health systems and health. Milbank Q. 2005;83(3):457-502. doi: 10.1111/j.1468-0009.2005.00409.x.
3. World Health Organization. Declaration on Primary Health Care [Internet]. Geneva, Switzerland: World Health Organization; 2018 [cited 2023 Aug 11]. Available: https://www.who.int/primary-health/conference-phc/declaration.
4. Waitangi Tribunal. Hauora report on stage one of the health services and outcomes inquiry. Wellington, New Zealand: Waitangi Tribunal; 2019.
5. Manatū Hauora – Ministry of Health. Health and Disability System Review – Final Report – Pūrongo Whakamutunga. Wellington, New Zealand; 2020.
6. The Royal New Zealand College of General Practitioners. 2022 Workforce Survey [Internet]. Wellington, New Zealand; 2022 [cited 2023 Aug 11]. Available: https://www.rnzcgp.org.nz/resources/data-and-statistics/2022-workforce-survey.
7. Gunja GZ, Gumas ED, Williams RD II, et al. Stressed Out and Burned Out: The Global Primary Care Crisis — Findings from the 2022 International Health Policy Survey of Primary Care Physicians [Internet]. Commonwealth Fund; 2022 [cited 2023 Aug 11]. Available from: https://doi.org/10.26099/j2ag-mx88.
8. General Practice New Zealand. Summary of closed books stock take 2022 [Internet]. Auckland, New Zealand: General Practice New Zealand; 2022 [cited 2023 Aug 11]. Available from: https://gpnz.org.nz/publications/pho-closed-books-stocktake-report-2022.
9. General Practice New Zealand. Te Puawāitanga o te Hāpori: Future possibilities of Primary Health Organisations [Internet]. Auckland, New Zealand: General Practice New Zealand; 2023 [cited 2023 Aug 11]. Available from: https://gpnz.org.nz/publications/te-puawaitanga-o-te-hapori.

Artificial intelligence in medicine: Promethean moment or Pandora's box?

Tim Eglinton, Isaac Tranter-Entwistle, Saxon Connor

The post-pandemic period has been a challenging time for health systems, both in New Zealand and globally. They have buckled under strain caused by a convergence of negative factors including the COVID-19 pandemic itself, chronic under-funding and inadequate workforces for dealing with ageing populations, producing a crisis of care provision that doesn't appear to have an immediate solution.[1]

This era has also seen the explosive growth of artificial intelligence (AI) powered applications across all aspects of our daily lives, which includes increasing momentum in medicine. As we approach the anniversary of the release of Open AI's Chat-GPT3, society has realised that the introduction of these large language models (LLMs) represents one of the most significant technological transformations in history. It is hailed as a new Promethean moment, rivalling other pivotal moments such as the inventions of the printing press, nuclear energy and the internet. The potential disruptive effect of this technology and AI in general is immense—as Microsoft's former chief strategist, Craig Mundie put it: "*this is going to change* everything *about how we do* everything".[2]

Does the transformative power of AI hold out hope for the future of healthcare, or have we opened a Pandora's box that will create more problems for the system than it solves?

"Artificial intelligence" is defined as the theory and development of computer systems with the ability to reason and perform cognitive functions such as problem solving, object and word recognition, and decision making. In addition to natural language processing applications such as Chat-GPT, it includes the overlapping subfields of machine learning, artificial neural networks and computer vision.

AI already has multiple established applications in healthcare. At the time of writing, no fewer than 80 AI-based algorithms or devices had gained FDA approval for clinical use for applications including analysing medical images and digital pathology slides, detecting drug interactions, identifying high-risk patients and coding medical notes.[3] AI algorithms have demonstrated equivalence with humans for performance in simple radiological, pathological and dermatological diagnostic tasks,[4–6] with recent clinical studies evidencing their positive impact on clinician performance with possible benefits for patient outcomes.[7] While such patient-centred applications have obvious benefits to individuals in terms of improving the accuracy and efficiency of reporting, other algorithms are deployed at a systems level, predicting key outcomes such as hospital readmission, mortality and sepsis.[8]

While these substantial gains have already been realised, the immediate future holds even more significant potential with the recent advent of *generative* AI such as Chat-GPT; that is, AI that can not only analyse huge volumes of text and other data, but also compose it. LLMs have the ability to rapidly synthesise high-volume, complex patient data and generate reports—for example, they could complete consultation notes or discharge summaries. Employing these algorithms may liberate clinician time to refocus on more patient-centred personal interactions, not only improving the patient experience but potentially reducing physician burnout.[9]

While AI has the potential to increase efficiency and optimise resource utilisation, it has pitfalls, unresolved issues and potential harmful consequences. The reliance of AI on huge datasets for model training has been a significant barrier to clinical progress. The sensitive nature of this healthcare data mandates that it be captured, stored and used in concordance with stringent ethical and privacy requirements, including protecting the rights of Indigenous peoples and recognising their data sovereignty. This is an area of rapidly evolving governance and regulation that, in the New Zealand context, has been supported by a recent update to the *Privacy Act* and the work of Te Mana Raraunga. Compounding this is the ongoing debate around data ownership among different stakeholders, with significant patient concern regarding the use of health data for potential commercial gain.

Where algorithms have been developed, the lack of clear reporting standards has made quality assessment difficult. This problem is exacerbated by the fact that algorithms often lack transparency, with deep learning models operating as "black boxes" that do not provide the basis of the reasoning behind their decisions, affecting the ability of patients and physicians alike to trust AI-generated recommendations and to achieve true informed consent for patients. This is further compounded by proprietary datasets' lack of transparency precluding demographic comparisons with the populations they are to be deployed in. Recognition of software as a medical device should ensure minimum safety standards are met, but human oversight will still be needed to ensure model outputs are context appropriate and add value to clinical practice, as was well illustrated by the challenges of using an AI model to screen for diabetic retinopathy in rural Thailand.[10] Even if the input data is appropriate, malfunctions remain a real threat to the clinical utility of AI algorithms; for example, it is well recognised that even the latest LLMs experience "hallucinations" producing wildly inaccurate outputs. If an algorithm does produce an error, the question of liability arises and whether this lies with the algorithm, the manufacturer or the treating doctor.

These concerns, specific to medicine, are amplified in the context of wider societal apprehension emerging in response to the exponential and unregulated development of AI. Of note, these concerns have been voiced by the creators of AI themselves, as evidenced by the results of a survey showing the majority of AI developers believe there is a more than 10% probability that humans will not be able to control further advancements in AI, leading to "human extinction".[11] Historian and author Yuval Noah Harari eloquently summarised the concerns of the power of LLMs and the potential for loss of human control of them. Harari postulates that humanity is defined by its ability to generate language and it represents the "operating system" of human culture, and as such "*AI's mastery of language means it can now hack the operating system of civilisation*".[12]

Despite the apprehension of and potential pitfalls with AI, there is no doubt it is here to stay and will have a huge impact on medicine going forward. Governance and regulatory bodies require agility to deal with the pace of change, such that it doesn't outstrip our ability to control it. In medicine this mandates engagement of clinicians in both the development and governance of AI.

As mentioned, AI algorithms rely on high-quality data for successful development and, in preparation for this, data science principles need to be integrated into clinical workflows as standard practice. An example from the authors' institution is the end-to-end data capture used for laparoscopic cholecystectomy (LC) including synoptic operating reports. This prospective, standardised, automatic data collection has already allowed for process analysis and the application of AI-powered algorithms for operative phase recognition and difficulty grading in LC and paves the way for automated operative report generation and computer vision-based audit of critical operative steps.[13,14] This integration of standardised data collection is all very well in a single institution; however, it needs to be implemented at a whole of system level. This has been recognised by the Artificial Intelligence for Health in New Zealand report,[15] the Digital Health Association and Health Informatics New Zealand. Examples of progress towards this goal include the establishment of the Te Whatu Ora Health Information Standards Organisation, i3 and initiatives such as Canshare, a national health informatics platform that aims to standardise the collection of data as part of clinical workflows. This has, for example, enabled progression of the authors' SynOPsys-CRC project to implement a standardised synoptic operating report for all colorectal cancer operations across New Zealand and Australia, an initiative that will provide high-quality data suitable for the development of AI algorithms to monitor the effect of operative process on outcomes.

Using these examples of AI in surgery serve to remind us that AI is an instrument and, much like a surgical instrument, it will work well if it is used properly, but if not it can do damage. AI is in a nascent phase in medicine but has already shown utility in many areas in the field and is here for the long term, even if it has opened a Pandora's box of regulatory, ethical and legal issues. Its potential to improve efficiency, accuracy and overall quality of care is so great the profession must confront these challenges. Overcoming them, allowing the benefits of AI to be leveraged, may at best provide a solution to the healthcare crisis and, at least, augment the performance of health professionals while leaving more time for doctor-patient interactions, making medicine more rewarding again for patients and doctors alike.

COMPETING INTERESTS

Tim Eglinton has undertaken consultancy for Touch Surgery™ (Touch Surgery™ is a subsidiary of Medtronic) including relating to the development of AI algorithms.

Isaac Tranter-Entwistle has received funding from Medtronic (Touch Surgery™ is a subsidiary of Medtronic) to undertake a PhD through the University of Otago from February 2021.

Saxon Connor has undertaken pro bono consultancy for Touch Surgery™ (Touch Surgery™ is a subsidiary of Medtronic) including relating to the development of AI algorithms.

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REFERENCES

1. Frizelle F. The present healthcare crises and the delusion of looking for an answer to this in the restructuring of the health system. N Z Med J. 2022;135(1561):12-14.
2. Friedman T. Our New Promethean Moment [Internet]. New York Times; 2023 Mar 21 [cited 2023 Aug 4]. Available from: https://www.nytimes.com/2023/03/21/opinion/artificial-intelligence-chatgpt.html.
3. The Medical Futurist. FDA-approved A.I.-based algorithms [Internet]. [cited 2023 Aug 4]. Available from: https://medicalfuturist.com/fda-approved-ai-based-algorithms/.
4. Rajpurkar P, Irvin J, Zhu K, et al. CheXNet: Radiologist-Level Pneumonia Detection on Chest X-rays with Deep Learning. ArXiv Prepr. 2017. arXiv:1711.05225.
5. Golden JA. Deep Learning Algorithms for Detection of Lymph Node Metastases from Breast Cancer: Helping Artificial Intelligence Be Seen. JAMA. 2017;318(22):2184-2186. doi: 10.1001/jama.2017.14580.
6. Esteva A, Kuprel B, Novoa RA, et al. Dermatologist-level classification of skin cancer with deep neural networks. Nature. 2017;542(7639):115-118. doi: 10.1038/nature21056.
7. Mohan BP, Facciorusso A, Khan SR, et al. Real-time computer aided colonoscopy versus standard colonoscopy for improving adenoma detection rate: A meta-analysis of randomized- controlled trials. EClinicalMedicine. 2020;29-30:100622. doi: 10.1016/j.eclinm.2020.100622.
8. Topol EJ. High-performance medicine: the convergence of human and artificial intelligence. Nat Med. 2019;25(1):44-56. doi: 10.1038/s41591-018-0300-7.
9. Atallah SB, Banda NR, Banda A, Roeck NA. How large language models including generative pre-trained transformer (GPT) 3 and 4 will impact medicine and surgery. Tech Coloproctol. 2023;27(8):609-614. doi: 10.1007/s10151-023-02837-8.
10. Murdock J. Google's AI Health Screening Tool Claimed 90 Percent Accuracy, but Failed to Deliver in Real World Tests [Internet]. Newsweek; 2020 Apr 4 [cited 2023 Aug 4]. Available from: https://www.newsweek.com/google-artificial-intelligence-deep-learning-health-research-thailand-clinics-diabetic-retinopathy-1500692.
11. AI Impacts. 2022 Expert Survey on Progress in AI [Internet]. 2020 [cited 2023 Aug 4]. Available from: https://aiimpacts.org/2022-expert-survey-on-progress-in-ai/.
12. Harari YN. You Can Have the Blue Pill or the Red Pill, and We're Out of Blue Pills [Internet]. New York Times; 2023 Mar 24 [cited 2023 Aug 4]. Available from: https://www.nytimes.com/2023/03/24/opinion/yuval-harari-ai-chatgpt.html.
13. Tranter-Entwistle I, Simcock C, Eglinton T, Connor S. Prospective cohort study of operative outcomes in laparoscopic cholecystectomy using operative difficulty grade-adjusted CUSUM analysis. Br J Surg. 2023;110(9):1068-1071. doi: 10.1093/bjs/znad046.
14. Tranter-Entwistle I, Eglinton T, Connor S, Hugh TJ. Operative difficulty in laparoscopic cholecystectomy: considering the role of machine learning platforms in clinical practice. Artificial Intelligence Surg. 2022;2:46-56. http://dx.doi.org/10.20517/ais.2022.01.
15. AI Forum New Zealand, Precision Driven Health. Artificial Intelligence for Health in New Zealand: Hauora i te Atamai Iahiko [Internet]. [cited 2023 Aug 10]. Available from: https://aiforum.org.nz/wp-content/uploads/2019/10/AI-For-Health-in-New-Zealand.pdf.

A retrospective observational study of the management of non-traumatic dental presentations at a tertiary centre in New Zealand: a Choosing Wisely approach

Calum Fisher, Oliver Sutcliffe, Peter Coghlan, Andrew McCombie, Laura Joyce

ABSTRACT

AIMS: Non-traumatic dental presentations (NTDPs) commonly present to emergency departments (EDs) and may receive orthopantomograms (OPGs, plain X-rays), opiates and antibiotics. "Choosing Wisely" is an international healthcare campaign that aims to reduce unnecessary and low-value patient care. This study aims to identify low-value management of NTDPs.

METHODS: Presentations to the Christchurch Hospital ED with dental pain or dental abscess in 2020 were included. Data collected included patient demographics, management and discharge medications. Descriptive statistics were calculated.

RESULTS: There were 931 NTDPs during the study period, with over-representation of young adults, Māori, Pacific Peoples and those living in high-deprivation areas. Of these, 343 (37%) received an OPG, of which 24% (83) were considered low value. Of patients managed by ED staff who were not referred to specialist dental services, 258 (42%) were prescribed antibiotics, of whom only half had facial swelling, and 71% received a script for analgesia, of which 78% included an opiate. Seventy-three percent of patients presented outside of normal working hours. Fewer than one in five NTDPs received definitive treatment.

CONCLUSIONS: NTDPs may receive non-optimal management in EDs. Continuing to care for NTDPs in this environment may add to increased healthcare costs, access block and poor opioid and antimicrobial stewardship.

Toothache, dental abscesses and other non-traumatic dental presentations (NTDPs) are a common presentation to emergency departments (EDs) in New Zealand.[1,2] The lack of accessible and affordable primary dental care has been linked to the increased presentation of NTDPs to hospitals, locally and internationally, with ethnic minorities and the most financially deprived being over-represented.[3,4] EDs are ill equipped to manage dental presentations without appropriate facilities, capacity and dentally trained staff. Low-acuity presentations contribute to burdens on EDs, hospital capacity and inpatient resources, and may impact on timely access to care for acute conditions.[5]

EDs may be an inappropriate environment for managing NTDPs, as non-dentally trained staff are unable to offer operative treatment. Extraction or pulp therapy is the most effective means of managing dental infection and tooth abscesses, yet are not routinely available at EDs.[6] New Zealand ED staff feel frustrated and powerless because they are not trained to manage dental conditions, cannot offer definitive treatment and cannot direct patients to affordable community options.[2] In an effort to diagnose and treat NTDPs, patients may undergo an orthopantomogram (OPG), a plain radiographic film, and be prescribed opioids and antibiotics.[7] However, without operative intervention, patients with NTDPs are likely to cyclically reattend ED, receive unnecessary imaging, opioids or antibiotics, and receive non-optimal care.[7]

"Choosing Wisely" is an initiative launched to improve the stewardship of resource use, encouraging patients and clinicians to discuss the appropriateness of common interventions.[8] The aim of this study is to assess whether we are "Choosing Wisely" by investigating the prevalence of unnecessary and low-value OPGs and the pharmacological prescribing habits for NTDPs.

Materials and methods

Study design

A retrospective observational study was conducted assessing NTDPs to the Christchurch Hospital ED from 1 January 2020 to 31 December 2020.

Setting

Christchurch Hospital is a tertiary-level hospital in Canterbury, New Zealand, that serves a population of approximately 580,000 people. The ED is the main acute referral centre in the region, with over 100,000 presentations annually.[9] NTDPs are managed by ED staff, with acute referrals to the Oral and Maxillofacial Service (OMS) for patients with significant swelling or systemic concerns. Local guidelines instruct ED staff referring patients with a facial swelling to request an orthopantomogram (OPG, plain X-ray). Non-acute follow-up may be available to eligible low-income patients with a Community Services Card via referral to the outpatient hospital dental service.

Participants

Patients with arrival complaints or discharge diagnoses of “toothache", “dental pain", “facial swelling” or “dental abscess” were included. Patients were excluded if presentations were not related to NTDPs, patients left before being seen by a doctor or were missing documentation.

Data collection

Data were extracted from clinical notes from the Christchurch Hospital’s electronic medical record system. All data were de-identified on extraction by the research team. Ethnicity data were classified as NZ European/Other, Māori, Pacific Peoples and Asian. Deprivation levels are reported as per the New Zealand Index of Deprivation (NZDep), displayed as deciles 1–10, with decile 1 representing the least deprived.

Data analysis

Data underwent descriptive statistical analysis with RStudio (Version 1.2.5033). Continuous data were assessed for normality, with medians and interquartile ranges (IQR) reported and compared using non-parametric tests. Odds ratios (OR) and 95% confidence intervals (CIs) were used for count data or Fisher tests for any cross-tabulation with zero cases in it.

Ethics

This study was granted ethical approval by the University of Otago Human Research Ethics Committee (HD21/032). In addition, locality authorisation (RO#21110) and Māori health endorsement were sought (#220429).

Results

Over the 1-year period there were 100,039 presentations to Christchurch Hospital. Of the 1,083 patients with relevant arrival complaints or discharge diagnoses, 152 of these presentations were excluded (Figure 1). The total patients included were 931, which accounted for 0.93% of ED presentations in 2020.

Demographics

Table 1 shows the demographic characteristics of patients. Of the presenting cohort, 54% were male, with a median age of 31 years (IQR 25–41). Patients aged 25–34 had the highest incidence of presentation at 36%. Māori (27%) and Pacific Peoples (7.4%) were over-represented compared to New Zealand European/Other. The NZDep for this cohort was not normally distributed, with a median of 6 (IQR 4–8) and 49% of patients in categories 7–10.

Clinical features

Patients with NTDPs were documented to have swelling (extraoral and/or intraoral) in 41.2% (384/931) of cases (Table 2). Extraoral swelling was present in 33.4% of cases (331/931) and intraoral swelling in 21.8% (201/931). Trismus was documented in 7.4% (69/931) of cases and tachycardia in 5.7% (53/931). Documentation of airway concern and cervical lymphadenopathy were recorded but not included as these features were either rare or poorly documented. NTDPs were triaged according to the Australasian Triage Score (ATS) from 1 to 5, with 5 representing the least clinically concerning. Seventy-two percent of patients were triaged as category 4 or 5.

Timing of presentation

Timing of presentations is presented in Table 2. Seventy-three percent of patients presented outside of normal working hours (8 am–4 pm weekdays), combining both weekends (34%, 316/931) and after-hours weekdays (39%, 367/931).

Length of stay

ED length of stay (LOS) median time was 2.3 hours (IQR 1.4–3.2) (Table 3). Referral to specialty and/or OPG influenced ED LOS. Patients referred to a specialty and who had an OPG had the longest ED LOS (median 3.3 hours, IQR 2.5–4.6). Patients who had an OPG but were not referred to a specialty spent a median 2.3 hours in ED (IQR 1.7–2.9). Patients who were not referred nor had an OPG had the shortest ED LOS (median 1.7 hours, IQR 1.1–2.5). For patients not referred to a specialty service, the addition of an OPG increased median ED LOS by 33 minutes (p<0.001). For patients referred to a specialty, the addition of an OPG increased median ED LOS by 12 minutes but was not statistically significant (p=0.51).

OPGs

Table 2 and 3 compare the characteristics and clinical management of patients who received OPGs with those who did not. OPGs were requested for 37% (343/931) of patients, with 75% (260/343) of them reviewed by a specialty. Twenty-four percent of patients who had an OPG requested by ED staff did not receive a specialty referral or intervention and were considered low value.

Patients who had an OPG were more likely to be referred to a specialty, receive surgical intervention and be admitted. This is likely because the local ED pathway requires OPGs prior to OMS referral, thus these patients were less likely to be discharged by ED staff and receive a dental block or a prescription.

Eighty-five patients (9.2%) were referred for specialty referral without an OPG. Among those who were referred to OMS, 69 were ED referrals, 12 were direct referrals from the community and three were reviewed by OMS with advice given prior to ED-led discharge. One patient was referred to general medicine for paracetamol overdose.

Figure 1: Flowchart of study design and inclusion/exclusion of patients.

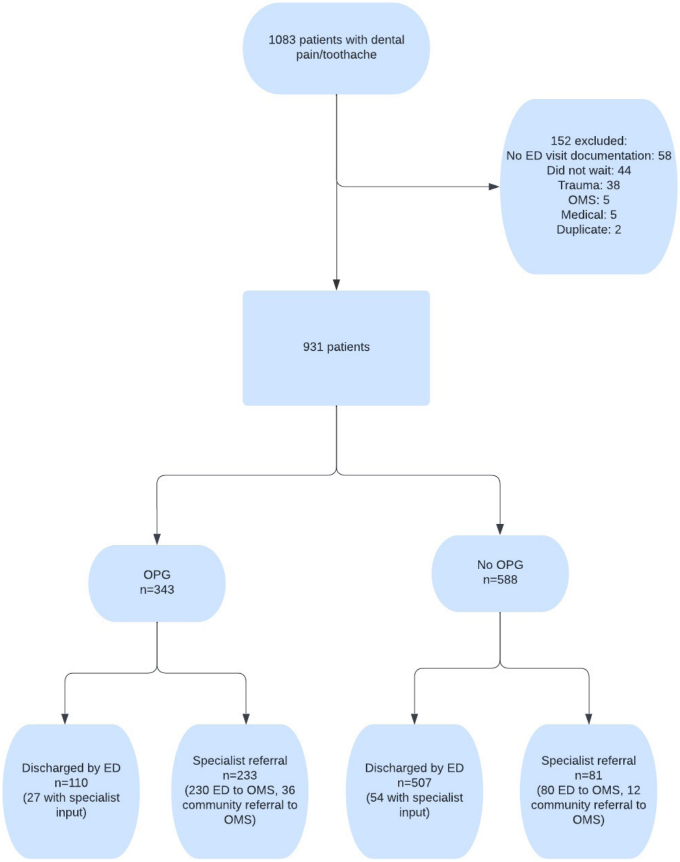

Table 1: Demographic characteristics of patients.

Patient characteristics	**Number of patients n (%)**	**Canterbury 2020/2021 population projection***
Age		
0–19	52 (5.6%)	24.2%
20–24	170 (18.3%)	7.00%
25–34	338 (36.3%)	14.7%
35–44	164 (17.6%)	12.6%
45–54	116 (12.5%)	13.1%
55–64	65 (7.0%)	12.2%
65+	26 (2.8%)	16.2%
Gender		
Male	507 (54.5%)	50.2%
Ethnicity		
New Zealand European/Other	570 (61.2%)	74.3%
Māori	252 (27.1%)	9.8%
Pacific Peoples	69 (7.4%)	2.8%
Asian	40 (4.3%)	13.1%
NZDep*		2018 Census**
1–5	384 (31.3%)	60.4%
6–10	546 (58.7%)	39.6%

* Does not equal total as one patient was international.
** Population projections prepared by StatsNZ[10] and NZ Deprivation data by University of Otago.[11]

Where patients were referred directly to OMS without an OPG, the OPG machine was documented to be under service in five cases, and five received a computed tomography (CT) scan rather than OPG. Of the remaining 59 patients, 29 received surgical intervention without an OPG, and the rest were reviewed only. Five patients had surgical intervention under general anaesthetic without an OPG; three were children and two had a CT scan prior.

Incidental findings were reported in 14 OPGs (4%), with most related to sinus mucosal thickening, which OPGs are poor to assess.[12] Three reports indicated possible dentigerous cysts.

Specialty management

Forty-two percent of patients (395/931) were referred to a specialty (of these, 20% were for advice only). Forty-one percent (162/395) of referrals were managed conservatively (non-surgical management and discharge). Surgical intervention was offered to 59% (232/395) of patients (Table 3).

Admission

Of the 931 patients, 4% (39) were admitted to the hospital, with 36 being admitted under OMS and three under general medicine. Among those admitted

Table 2: Patient characteristics—OPG vs non-OPG.

	OPG n (%)	**Non-OPG n (%)**	**Odds ratio**
Number of patients	**343**	**588**	
Clinical features reported in ED*			
Extraoral swelling present	192	119	**5.0 (3.7–6.7)**
Intraoral swelling present	98	105	**1.8 (1.3–2.5)**
Trismus present	45	24	**3.5 (2.1–5.9)**
Tachycardic at presentation	36	17	3.9 (2.2–7.1)
Swelling (extraoral and/or intraoral) present	208	176	**3.6 (2.7–4.8)**
Gender			
Male	190 (55)	317 (54)	1.1 (0.8–1.4)
Ethnicity			
European	203 (59)	347(59)	1 (ref)
Māori	94 (27)	158 (27)	1.0 (0.7–1.4)
Pacific Peoples	28 (8)	41 (7)	1.2 (0.7–1.9)
Asian	15 (4)	25(4)	1.0 (0.5–2.0)
Middle Eastern/Latin American/African/Other	3 (<1)	17 (3)	0.3 (0.1–1.0)
NZDep**			
1–5	142	242	**1.0 (0.8–1.3)**
6–10	201	345	**1.0 (0.8–1.3)**
Timing of presentation			
During working hours (8 am–4 pm)	112 (33)	136 (23)	1.3 (0.9–1.8)
Weekday after hours (4 pm–8 am)	106 (31)	261 (44)	0.6 (0.5–0.9)
Weekend	125 (36)	191 (33)	1 (ref)
After hours (weekday 4 pm–8 am and weekend)	231 (67)	452 (77)	**0.6 (0.5–0.8)**

* Where values do not equal total, data points were “not documented”.
** Does not equal total as one patient was international.

Table 3: Clinician management—OPG vs non-OPG.

	OPG n (%)	**Non-OPG n (%)**	**Statistics◙**
Number of patients	**343**	**588**	
ED management			
ED, no specialty input	83 (24.2)	453 (77.0)	1 (ref)
Specialty referral, seen at presentation◙	232 (67.6)	85 (14.5)	**14.9 (10.6–21.0)**
Specialty referral, not seen at presentation	28 (8.2)	50 (8.5)	**3.1 (1.8–5.1)**
Median ED length of stay (hours)			
No specialty referral	2.25 (IQR 1.7–2.9)	1.66 (IQR 1.1–2.5)	**p-value=<0.001**
Specialty referral	3.25 (IQR 2.5–4.6)	3.05 (IQR 2.6–4.2)	p-value=0.51
ED prescribing*			
Discharged no Rx	19 (5)	101 (17)	**0.3 (0.2–0.5)**
Discharged with Rx	91 (27)	406 (69)	**0.2 (0.1–0.2)**
Discharged Rx including analgesia	76 (22)	365 (62)	**0.2 (0.1–0.2)**
Includes opioid	60 (18)	274 (47)	**0.2 (0.2–0.3)**
Discharged Rx including antibiotics	66 (19)	192 (33)	**0.5 (0.4–0.7)**
Augmentin	55 (16)	132 (22)	**0.7 (0.5–0.9)**
Amoxicillin	9 (3)	40 (7)	**0.4 (0.2–0.8)**
Other	2 (<1)	20 (3)	**0.2 (<0.1–0.7)**
Swelling (extraoral and/or intraoral) present	37 (11)	95 (16)	**0.6 (0.4–0.9)**
LA administered	7 (2)	39 (7)	**0.3 (0.1–0.7)**
Acute management†			
Conservative management ED	83 (24)	453 (77)	1 (ref)
Conservative management specialty	71 (21)	91 (15)	**4.3 (2.9–6.3)**
ED I&D LA	37 (11)	16 (3)	**12.6 (6.7–23.7)**
ED Exo LA	127 (37)	23 (4)	**30.1 (18.2–49.8)**
Extraction/I&D GA	24 (7)	5 (<1)	**26.2 (9.7–70.6)**
Admission/discharge□			
Admitted	29 (9)	10 (2)	**5.3 (2.6–11.1)**
Discharged	313 (91)	578 (98)	1 (ref)
Admission ward (specialty, OMS)	21	8	**13.4 (5.8–31.1)**

Table 3 (continued): Clinician management—OPG vs non-OPG.

Admission ward (specialty, other)	2	1	**10.2 (0.9–113.6)**
Admission HDU/ICU (OMS only)	6	1	**30.6 (3.6–257.0)**
Discharged by ED with f/u community	93	474	1 (ref)
Discharged by ED with f/u OMS	17	33	**2.6 (1.4–4.9)**
Discharged by OMS with f/u specialty	69	23	**15.3 (9.1–25.8)**
Discharged by OMS with f/u community	131	48	**13.9 (9.3–20.7)**
Self-discharged	3	0	**p-value=0.005**

◙All values refer to odds ratio with confidence intervals in parenthesis unless specified, apart from Median ED length of stay (hours), which is a Mann–Whitney U test, and Admission/discharge: self-discharged, which is a Fisher test.
*Specialty referral includes patients referred to the Oral and Maxillofacial service (OMS); however, it also includes <5 patients referred to other specialties. An example is a patient referred to General Medicine with dental pain and diabetic ketoacidosis.
†Includes three patients reviewed by OMS but discharged by ED.
Rx refers to the prescription given to a patient on discharge.

□OPG acute management and admission/discharge does not equal total as one patient's management was not documented.

under OMS, 75% (27) required dental extraction and/or associated incision and drainage performed under general anaesthetic and 26% (7) required monitoring in a high dependency or intensive care unit after the procedure.

Discharge

Of 931 patients, 746 (80%) were directly discharged to the community, with 567 (76%) discharged by ED staff and 179 (24%) by the OMS team. Approximately 15% (142/931) had out-patient follow-up arranged with either OMS or hospital dental services.

ED management and prescribing on discharge

ED staff managed 66% (614/931) of NTDPs. Of these, 7.5% (46/614) received long-acting local anaesthetic. A total of 617 patients were discharged by ED, of which 81% (497/617) received a prescription, with analgesia being the most prescribed medication in 89% (441/497) of prescriptions. Of these, 78% (334/441) included some form of opioid, most commonly codeine (81% 270/334), followed by tramadol (17% 57/334) and morphine (2% 8/334). For 11 patients, prescriptions were not documented but their notes mentioned some form of take-home analgesia or written prescription.

Antibiotics were prescribed in 52% (258/497) of cases with amoxicillin/clavulanic acid being the most prescribed (72%, 187/258), followed by amoxicillin (19%, 49/258) and various others (7%, 20/258 including cephalosporins, tetracyclines, aminoglycosides, sulfonamides, macrolides and nitroimidazoles). Of the 258 patients prescribed antibiotics on discharge, 49% (126) did not have documented extraoral or intraoral swelling.

Racial inequity

Māori were over-represented in NTDPs, accounting for 27% of all presentations in comparison to a regional population projection of 9.8%.[10] Māori patients were younger and more deprived than non-Māori, with a median age of 28 and NZDep of 7 (Table 4). They were more likely to present with clinical features of intraoral swelling and trismus; however, there was no association with extraoral swelling or tachycardia. Māori patients were more likely to present during working hours (OR 1.6 [1.1–2.4 95% CI]), but there were no statistically significant differences in ED LOS, specialty referral, management or admission and discharge between Māori and non-Māori patients. Māori were less likely to be prescribed "Other" antibiotics (OR 0.2 [0.1–0.9])

Table 4: Patient characteristics and clinical management—Māori vs non-Māori.

	Māori n (%)	**Non-Māori n (%)**	**Statistics◙**	**Statistics controlling for age**
Number of patients	**252**	**679**		**N/A**
Patient characteristics				
Male	134 (53)	373 (55)	0.9 (0.7–1.2)	1.0 (0.8–1.4)
Age (median)	28	32	**p-value=<0.001**	**N/A**
NZDep (median)	7	6	**p-value=0.01**	**p=0.04**
Clinical features reported in ED*				
Extraoral swelling present	92	219	1.2 (0.9–1.6)	1.3 (0.9–1.8)
Intraoral swelling present	68	135	**1.5 (1.1–2.1)**	**1.5 (1.1–2.1)**
Trismus present	27	42	**1.8 (1.1–3.0)**	**1.7 (1.0–2.9)**
Tachycardic at presentation	12	41	0.8 (0.4–1.5)	0.7 (0.3–1.3)
Timing of presentation				
During working hours (8 am–4 pm)	82 (33)	166 (24)	**1.6 (1.1–2.4)**	**1.7 (1.1–2.6)**
Weekday after hours (4 pm–8 am)	97 (39)	270 (40)	1.2 (0.8–1.7)	1.1 (0.7–1.7)
Weekend	73 (29)	243 (36)	1 (ref)	1 (ref)
Total after hours	170 (67)	513 (76)	0.7 (0.5–0.9)	0.6 (0.4–0.8)
ED management†				
ED, no specialty input	144 (57)	392 (58)	1 (ref)	1 (ref)
Specialty referral, seen at presentation	86 (34)	231 (34)	1.0 (0.7–1.4)	1.1 (0.8–1.6)
Specialty referral, not seen at presentation	22 (9)	56 (8)	1.1 (0.6–1.8)	1.2 (0.7–2.0)
OPG	94 (37)	249 (36)	1.0 (0.8–1.4)	1.2 (0.9–1.6)
Median ED length of stay (hours)				
No specialty referral	1.85 (IQR=1.1–2.7)	1.73 (IQR=1.1–2.5)	p-value=0.79	p=0.49
Specialty referral	3.22 (IQR=2.8–4.7)	3.13 (IQR=2.5–4.4)	p-value=0.45	p=0.1
No OPG	1.87 (IQR=1.1–3.0)	1.76 (IQR=1.2–2.7)	p-value=0.54	p=0.85

Table 4 (continued): Patient characteristics and clinical management—Māori vs non-Māori.

OPG	3.18 (IQR=2.2–3.6)	2.95 (IQR=2.1–4.0)	p-value=0.89	p=0.38
Specialty referral + OPG	3.22 (IQR=2.7–4.8)	3.25 (IQR=2.5–4.6)	p-value=0.76	p=0.12
No specialty referral + no OPG	1.67 (IQR=1.1–2.6)	1.66 (IQR=1.1–2.5)	p-value=0.83	p=0.42
ED prescribing□				
Discharged no Rx	31 (12.3)	89 (13.1)	0.9 (0.6–1.4)	0.8 (0.5–1.3)
Discharged with Rx	136 (54.0)	361 (53.2)	1.0 (0.8–1.4)	1.0 (0.7–1.3)
Discharged Rx including analgesia	126 (50.0)	315 (46.3)	0.9 (0.7–1.2)	1.0 (0.8–1.4)
Includes opioid	97 (38.5)	237 (35.0)	1.2 (0.9–1.6)	1.1 (0.8–1.5)
Discharged Rx including antibiotics	70 (27.8)	188 (27.7)	1.0 (0.7–1.4)	1.0 (0.7–1.4)
Augmentin	54 (21.4)	133 (19.6)	1.1 (0.8–1.6)	1.1 (0.8–1.6)
Amoxicillin	14 (5.6)	35 (5.2)	1.1 – (0.6–2.0)	1.1 (0.6–2.1)
Other	2 (<1)	20 (2.9)	0.3 (0.1–0.9)	0.2 (0.1–0.9)
LA	16 (4.7)	30 (5.1)	1.5 (0.8–2.7)	1.4 (0.7–2.6)
Acute management§				
Conservative management ED	144 (57.1)	392 (57.8)	1 (ref)	1 (ref)
Conservative management specialty	42 (16.7)	120 (17.7)	1.0 (0.6–1.4)	1.0 (0.7–1.5)
ED I&D LA	11 (4.4)	42 (6.2)	0.7 (0.4–1.4)	0.8 (0.4–1.5)
ED Exo LA	45 (17.9)	105 (15.5)	1.2 (0.8–1.7)	1.4 (1.0–2.2)
Extraction/I&D GA	10 (4.0)	19 (2.8)	1.4 (0.7–3.2)	1.3 (0.6–2.9)
Admission/discharge§				
Admitted	13 (5.2)	26 (3.8)	1.4 (0.7–2.7)	1.3 (0.6–2.6)
Discharged	239 (94.8)	652 (96.0)	1 (ref)	1 (ref)
Admission ward (specialty, OMS)	12	17	2.0 (0.9–4.3)	2.0 (0.9–4.4)
Admission ward (specialty, other)	1	2	1.4 (0.1–15.9)	1.7 (0.1–19.1)
Admission HDU/ICU (OMS only)	0	7	p=0.2 (Fisher test)	N/A
Discharged by ED with f/u community	147	420	1 (ref)	1 (ref)

Table 4 (continued): Patient characteristics and clinical management—Māori vs non-Māori.

Discharged by ED with f/u OMS	19	31	1.8 (1.0–3.2)	1.9 (1.0–3.6)
Discharged by OMS with f/u specialty	26	66	1.1 (0.7–1.8)	1.3 (0.8–2.1)
Discharged by OMS with f/u community	47	132	1.0 (0.7–1.5)	N/A
Self-discharged	0	3	p=0.6 (Fisher test)	

▣All values refer to odds ratio with confidence intervals in parenthesis unless specified, apart from Median ED length of stay (hours), which is a Mann–Whitney U test, and Admission/discharge: self-discharged, which is a Fisher test.
*Where values do not equal total, data points were "not documented".
†Specialty referral includes patients referred to the Oral and Maxillofacial service (OMS); however, it also includes <5 patients referred to other specialties.
□Includes three patients reviewed by OMS, but discharged by ED.
§Non-Māori acute management and Admission/discharge does not equal total as one patient's management was not documented.
Rx refers to the prescription given to a patient on discharge.
N/A = not applicable.

Discussion

The "Choosing Wisely" campaign is a global initiative aimed at promoting responsible use of healthcare resources.[8] This study investigated the management of NTDPs in a large tertiary ED in New Zealand, including the utilisation of OPGs and prescription of opioids and antibiotics.

The study's demographics of NTDPs align with previous research, showing over-representation among young adults, Māori, Pacific Peoples and those living in high deprivation areas.[1,2] These findings have not changed since they were reported in the New Zealand Oral Health Survey a decade ago.[4] A recent audit at Christchurch Hospital found that referral rates to OMS services had doubled from 2018–2020, with higher rates for Māori and Pacific Peoples.[13] When compared to referral rates of a similar 2008–2009 study, this suggests a worsening of oral health inequity for Māori in this region.[14]

Most NTDPs were low severity and managed by non-dentally trained ED staff. This is reflected in the high rates of discharge to the community (80%), and low rates of treatment under general anaesthesia (3%) or admission to hospital (4%). Cost and access to private dental care have been suggested as reasons for NTDPs presenting to the ED, rather than severity.[4] NTDPs are largely preventable through appropriate preventive and community dental care, and their presentation in EDs represents failures in primary dental care.[3] The consequences of low-acuity presentations cannot be underestimated, as NTDPs account for up to 1% of all ED presentations in some New Zealand hospitals, placing significant burden on an already overstrained healthcare system.[1,15]

Although there is limited literature on the use of radiological investigations for NTDPs in the ED setting, the authors suggest that OPGs be considered only when significant facial swelling or systemic signs necessitate surgical intervention. For the clinically stable patients, OPGs are unlikely to provide additional value, as most patients receive palliative symptom management. Unnecessary OPGs contribute to prolonged ED LOS, access block and radiation exposure.[5] In our study, we identified that 24% of OPG requests were not aligned with specialist referrals and were likely of low value. The reasons behind OPG requests in the ED were not evaluated, but they may aim to enhance patient flow and facilitate specialist referrals.[16] Additionally, some patients underwent surgical intervention without an OPG, raising questions about the necessity or prior availability of imaging. This highlights the need to consider whether ED staff should request OPGs for all NTDPs referred to OMS.

Our study investigated opioid and antibiotic prescribing for NTDPs in EDs. Among patients managed by ED, 54% (334/617) were prescribed opioids for pain relief with codeine being the most common despite its modest efficacy in managing acute dental pain and potential for adverse effects.[17,18] A 2018 overview of 5 systematic reviews suggests combinations of ibuprofen and paracetamol are more effective than any opioid and produce lower incidence of adverse events and potential for abuse.[17–20] Furthermore, opioid prescribing in the ED may contribute to long-term use and addiction, which is particularly concerning given the potential for NTDPs to cyclically reattend.[21,22]

To mitigate opioid prescribing for NTDPs, implementing workflow solutions such as utilising long-acting local anaesthetic can be effective.[17,21] Dental nerve blocks, when included in prescribing guidelines, have been shown to reduce opioid prescription rates.[23] However, despite 7% of patients receiving dental blocks in this study, 57% were still prescribed opioids upon discharge. Although the study did not examine the administration pattern of dental blocks, inadequate training and patient acceptance could be barriers to ED staff performing them.[21]

Antibiotics being prescribed for acute dental conditions has come under greater scrutiny among concerns of increasing antibiotic resistance.[22] A recent systematic review by the American Dental Association emphasises the importance of prioritising definite dental treatment for patients with NTDPs and avoiding antibiotic prescriptions for those without localised or systemic features. Delayed prescriptions for amoxicillin or penicillin V are recommended for patients with a localised abscess but no immediate access to definitive treatment. In an ED setting, physicians should assess patients' access to oral healthcare and determine the necessity of immediate antibiotic prescriptions. If definitive treatment is available for patients with localised abscess, antibiotics are not recommended. For cases with systemic involvement, antibiotics and urgent referral for definitive treatment are advised.[24] These guidelines highlight that where access to definitive treatment is available, unnecessary antibiotic prescribing can be prevented.

The review also highlights that narrow-spectrum antibiotics (amoxicillin) are effective for managing dental swellings, whereas broad-spectrum antibiotics (amoxicillin/clavulanic acid) are unnecessary unless the infection is severe or initial treatment has failed.[24,25] However, in our study, 258 out of 617 (42%) patients managed by ED were prescribed antibiotics, with only half of them having facial swelling. Surprisingly, amoxicillin/clavulanic acid was the most prescribed antibiotic (74%), yet only 47% of this group had documented swelling. This over-reliance on broad-spectrum antibiotics at our centre is concerning, as it contradicts the current guidelines for NTDPs and differs from international prescribing habits.[22] The observed disparities may stem from insufficient training in dental condition management and a tendency to take action when feeling powerless.[2,26] Over-prescribing opioids and antibiotics for NTDPs without access to definitive treatment can perpetuate cyclic reattendance and is inconsistent with principles of antimicrobial stewardship and Choosing Wisely.[8] Addressing these issues is crucial for promoting appropriate prescribing practices and improving patient outcomes.

The financial implications of managing NTDPs in the ED are significant. In New Zealand, eligibility for care of dental conditions is determined not only by the severity of the presenting condition but also by an individual's income threshold and possession of a Community Services Card.[2] In 2018, the cost of a visit to a New Zealand ED was estimated to be NZ $370.[27] Therefore, in 2020, Christchurch ED likely incurred a minimum cost of $344,470 for NTDP management, which primarily provided symptomatic relief. When considering operative treatment as the appropriate intervention, fewer than one in five NTDPs received definitive treatment. In contrast, a simple extraction in a private dental practice in Canterbury averages $233.[28] Allocating public funds to provide temporary symptomatic relief in this manner is ineffective and may contribute to cyclic reattendance.

Our study emphasises that the ED environment is not optimal for managing NTDPs and failings in primary healthcare services must be addressed to enable routine and urgent dental care. On a background of calls for increasing targeted or universally funded dental care, a policy report in 2019 estimated that providing basic dental services for low-income adults in New Zealand would generate a return of $1.60 for each dollar invested, due to reduced health services costs, increased employment and tax revenue.[29] Reorienting oral health services to establish community-based relief-of-pain services or contracting private dentists to provide affordable and after-hours dental care to low-income individuals could provide viable referral avenues for NTDPs presenting to EDs and reduce inappropriate antibiotic and opioid prescribing.[2] Without significant change, socially and economically disadvantaged individuals will continue to have limited access to primary dental care and rely on ill-equipped EDs for care.

Strengths and limitations

To our knowledge, this is the first investigation into the management and prescribing habits of ED staff for NTDPs in New Zealand hospitals. However, limitations of this study include potential variability in the management of NTDPs across New Zealand hospitals due to differences in demographics and resource distribution. Furthermore, this hospital serves a large population that lacks community water fluoridation, which is known to provide the most benefit to disadvantaged socio-economic groups.[30] Additionally, the retrospective nature of the study relies on the accuracy and completeness of clinical documentation.

The observational study also covered periods of enforced public lockdown due to COVID-19, which may have affected management, presentation patterns and referral rates. Referral rates to OMS during the lockdown period of 2020 were found to be lower when compared to the year previous; however, rates of referral to OMS services for the entire year were still increased compared to the year prior.[13]

Conclusion

This observational study examined the management of patients presenting with NTDPs to an ED in New Zealand. Most NTDPs were low severity and managed by non-dentally trained ED staff. NTDPs may receive non-optimal care in this environment, which may contribute to increased healthcare costs, access block for time-critical patients, unnecessary radiation exposure and poor opioid and antimicrobial stewardship.

COMPETING INTERESTS

Nil.

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REFERENCES

1. Mckenzie J, Yap M, Phemister R, Singh T. A five-year retrospective observational study of dental presentations to Waikato Hospital’s emergency department. N Z Med J. 2022;135(1551): 95-105.
2. Smith M, Stroud C, Low M, et al. Non-traumatic dental presentations at emergency departments in New Zealand. N Z Med J. 2021;134(1544):99-112.
3. Whyman RA, Mahoney EK, Morrison D, Stanley J. Potentially preventable admissions to New Zealand public hospitals for dental care: a 20-year review. Community Dent Oral Epidemiol. 2014;42(3):234–44. DOI: 10.1111/cdoe.12073.
4. Manatū Hauora – Ministry of Health. Our Oral Health: Key findings of the 2009 New Zealand Oral Health Survey [Internet]. Wellington: Manatū Hauora – Ministry of Health; 2010 [cited 2022 Sep 7]. Available from: https://www.health.govt.nz/publication/our-oral-health-key-findings-2009-new-zealand-oral-health-survey.
5. Jones PG, Mountain D, Forero R. Emergency department crowding measures associations with quality of care: A systematic review. Emerg Med Australas. 2021;33(4):592-600.
6. National Institute for Health and Care Excellence. Summary of antimicrobial prescribing guidance – managing common infections. Public Health England. 2020 [cited 2022 Oct 6]. Available from: https://www.birminghamandsurroundsformulary.nhs.uk/docs/files/NICE%20Primary%20Care%20summary-antimicrobial-prescribing-guidance%20Jan%202022.pdf?UNLID=95863575720221250453.
7. Bassey O, Csikar J, Hallam J, et al. Non-traumatic dental presentations at accident and emergency departments in the UK: a systematic review. Br Dent J. 2020;228(3):171-6. doi: 10.1038/s41415-020-1247-x.
8. Choosing Wisely [Internet]. ABIM Foundation. [cited 2022 May 31]. Available from: https://www.choosingwisely.org/.
9. Te Whatu Ora – Health New Zealand Waitaha Canterbury. Emergency Department presentations 2020-21 [Internet]. 2022 Apr [cited 2022 Jun 17]. Available from: https://www.cdhb.health.nz/about-us/document-library/10803-emergency-department-presentations-2020-21/.
10. Te Whatu Ora – Health New Zealand Waitaha Canterbury. Population projections for Canterbury. [Internet]. Canterbury DHB; 2020 [cited 2022 Oct 15]. Available from: https://www.cdhb.health.nz/about-us/document-library/cdhb-10466-population-projections-canterbury/.
11. University of Otago Wellington. Socioeconomic Deprivation Indexes: NZDep and NZiDep, Department of Public Health [Internet]. University of Otago; 2020 [cited 2022 Oct 15]. Available from: https://www.otago.ac.nz/wellington/departments/publichealth/research/hirp/otago020194.html.
12. Constantine S, Clark B, Kiermeier A, Anderson PP. Panoramic radiography is of limited value in the evaluation of maxillary sinus disease. Oral Surg Oral Med Oral Pathol Oral Radiol. 2019;127(3):237-46. doi: 10.1016/j.oooo.2018.10.005.
13. Graham D, Schuurman N, Willink R, Erasmus J. Draining infections and draining resources: The nature and cost of acute odontogenic infection referrals to the Oral and Maxillofacial Surgical Service at Christchurch Hospital. N Z Dent J. 2022;118:137-46.
14. Hwang T, Antoun JS, Lee KH. Features of odontogenic infections in hospitalised and non-hospitalised settings. Emerg Med J. 2011;28(9):766-9. doi: 10.1136/emj.2010.095562.
15. Davis EE, Deinard AS, Maïga EW. Doctor, my tooth hurts: the costs of incomplete dental care in the emergency room. J Public Health Dent. 2010;70(3):205-10. doi: 10.1111/j.1752-7325.2010.00166.x.
16. Morley C, Unwin M, Peterson GM, et al. Emergency department crowding: A systematic review of causes, consequences and solutions. PLoS One. 2018;13(8):e0203316. doi: 10.1371/journal.

pone.0203316.

17. Dionne R, Gordon SM, Moore PA. Prescribing Opioid Analgesics for Acute Dental Pain: Time to Change Clinical Practices in Response to Evidence and Misperceptions [Internet]. CONTINUING EDUCATION 1 | PAIN MANAGEMENT. [cited 2022 May 30]. Available from: http://www.rwcds.org/wp-content/uploads/2012/12/Compendium_June-2016.pdf.
18. Moore PA, Ziegler KM, Lipman RD, et al. Benefits and harms associated with analgesic medications used in the management of acute dental pain: An overview of systematic reviews. J Am Dent Assoc. 2018;149(4):256-265.e3. doi: 10.1016/j.adaj.2018.02.012.
19. Rigert JM, Napenas JJ, Wally M, et al. Dental pain management with prescription opioids by nondental healthcare professionals in a healthcare system network. J Public Health Dent. 2022;82(1):22-30. doi: 10.1111/jphd.12459.
20. Aminoshariae A, Kulild JC, Donaldson M, Hersh EV. Evidence-based recommendations for analgesic efficacy to treat pain of endodontic origin: A systematic review of randomized controlled trials. J Am Dent Assoc. 2016;147(10):826-39. doi: 10.1016/j.adaj.2016.05.010.
21. Patel NA, Afshar S. Addressing the high rate of opioid prescriptions for dental pain in the emergency department. Am J Emerg Med. 2018;36:138-9.
22. Oluwatosin A, Trop B, Kreuser K, et al. Antibiotic and opioid prescribing for simple toothache in the emergency department. Am J Emerg Med. 2022;60:220-2. doi: 10.1016/j.ajem.2022.07.010.
23. Fox TR, Li J, Stevens S, Tippie T. A performance improvement prescribing guideline reduces opioid prescriptions for emergency department dental pain patients. Ann Emerg Med. 2013;62(3):237-40. doi: 10.1016/j.annemergmed.2012.11.020.
24. Lockhart PB, Tampi MP, Abt E, et al. Evidence-based clinical practice guideline on antibiotic use for the urgent management of pulpal- and periapical-related dental pain and intraoral swelling: A report from the American Dental Association. J Am Dent Assoc. 2019;150(11):906-921.e12. doi: 10.1016/j.adaj.2019.08.020.
25. Teoh L, Cheung MC, Dashper S, et al. Oral Antibiotic for Empirical Management of Acute Dentoalveolar Infections-A Systematic Review. Antibiotics (Basel). 2021;10(3):240. doi: 10.3390/antibiotics10030240.
26. Ooi K. The Pitfalls of Overtreatment: Why More Care is not Necessarily Beneficial. Asian Bioeth Rev. 2020;12(4);399:417. doi: 10.1007/s41649-020-00145-z.
27. Pharmac. Cost Resource Manual [Internet]. 2018 [cited 2022 Sep 3]. Available from: https://pharmac.govt.nz/medicine-funding-and-supply/the-funding-process/policies-manuals-and-processes/economic-analysis/cost-resource-manual/.
28. New Zealand Dental Association. 2020 Fee Survey [Internet]. 2020 [cited 2023 Mar 5]. Available from: https://www.nzda.org.nz/assets/files/Public/Resources/Fee_Survey_2020.pdf.
29. New Zealand Dental Association. Access to Oral Health Services for Low Income Adults: Building on our policy position [Internet]. 2019 Oct [cited 2023 Mar 5]. Available from: https://www.nzda.org.nz/assets/files/Access_To_Oral_Health_Services_For_Low_Income_Adults.pdf.
30. Office of the Prime Minister’s Chief Science Advisor, Royal Society of New Zealand. Health effects of water fluoridation: A review of the scientific evidence [Internet]. 2014 [cited 2023 Feb 21]. Available from: https://www.royalsociety.org.nz/assets/documents/Health-effects-of-water-fluoridation-Aug-2014-corrected-Jan-2015.pdf.

How young people in Aotearoa perceive vaping and the associated oral health risks

Hillary Hang, Rosie Dobson, Judith McCool

ABSTRACT

AIMS: The use of electronic cigarettes (EC) among young people has escalated in Aotearoa and in other jurisdictions where they are available commercially. The rise in vaping among young people for lifestyle reasons rather than for smoking cessation is of concern, given the growing evidence of the harmful effects of vaping. Specifically, there is little known about how young people in Aotearoa perceive the effect of vaping on their oral health. This study aims to explore how young people in Aotearoa perceive risks of vaping on oral health.

METHODS: A cross-sectional online survey (n=237) was conducted to explore young people's (16–24 years) perceptions, current practices and attitudes regarding vaping and oral health.

RESULTS: Although most participants understood that vaping posed risks to their general health, they reported lower levels of perceived risk of vaping on oral health. Current vapers held significantly lower perceptions of both the addictiveness and harms associated with vaping. Participants reported that oral health professionals seldom asked them about their vaping status. Most participants were open to discussing with oral health professionals the effects of vaping on their oral health, suggesting that they would be less likely to vape if they knew it was bad for their oral health.

CONCLUSIONS: The findings indicate that there is a need for improved information for young people communicating the potential oral health risks of vaping and that oral health professionals are a way to disseminate this information.

The use of electronic cigarettes (EC) or vaping among young people has escalated, not just in Aotearoa, but globally, in jurisdictions where the products are accessible.[1] Although current regulations in Aotearoa prohibit the sale of vaping products to anyone under the age of 18 years, previous research has shown that vaping is becoming increasingly popular among adolescents (15–17 years old).[2] Over 40% of adolescents in Aotearoa have vaped at some point in their lives, and about 10% of them use EC daily.[2] The 2021/22 New Zealand Health Survey (NZHS) has revealed that young people have the highest rate of daily EC use (22.9%) among all age groups.[3] The *Smokefree Environments and Regulated Products (Smoked Tobacco) Amendment Act* came into force in January 2023.[4] This Act incorporates several provisions, including: to lower the maximum nicotine amount allowed in smoked tobacco products, reduce the number of tobacco sales locations and ensure that tobacco is never advertised to anyone who was born on or after January 1, 2009 (to create a "smokefree generation"). According to the most recent NZHS,[3] smoking rates are continuing to fall, with less than 8% of adults smoking daily in Aotearoa—a historic low. The advent of EC has been a contributor to this result but poses important collateral risks to young people who choose to vape for reasons other than to quit tobacco.

Recent studies suggest that EC use can be harmful to general and oral health. Information on young people's perceptions of vaping's effects on health indicate that it is seldom considered benign; yet, when compared to tobacco, the perceived risk to health is often dismissed or minimised.[5–8] Research into the effects of vaping on oral health is beginning to emerge, with evidence indicating that the nicotine and other chemical compounds in EC liquids and vapour may be associated with oral health issues.[1,9–15] Although a range of potential oral health effects have been reported, periodontal damage and irritation of the mouth and throat are the most commonly reported oral health effects.[7,14–15] There is currently no research that we are aware of that describes how young people perceive the risk of vaping on their oral health in Aotearoa.

Vape products are highly accessible and affordable in Aotearoa. They have also been heavily promoted and evidence suggests that they are being targeted to young people for lifestyle reasons.[16–18] Vape product packaging and point-of-sale marketing provide very general warnings,[17,19] with the potential effects on oral health never mentioned. In the interests of providing accessible, people-centred cessation support in healthcare facilities such as hospitals and dental clinics, patients are routinely asked if they smoke, but it is unclear whether they are also routinely asked if they vape.[20–22]

Although many studies have been conducted to investigate people's knowledge and attitudes concerning vaping on general health, few have investigated the perceived risk of vaping on personal oral health.[23–25] To date, it is unclear how young people in Aotearoa perceive the potential negative effects on their general and oral health. Oral health is among the most neglected areas of health for young people, and yet the impacts are financially and socially damaging. This work is the first in Aotearoa to focus on vaping and oral health in young people. The purpose of this study was to learn how young people (16–24 years old) perceive vaping and the associated oral health risks. This information could be useful to support national efforts to reduce uptake among non-smokers and vapers.

Methods

Study design

A cross-sectional online survey was conducted between August and September 2022 in Aotearoa. The questionnaire was delivered online using the Qualtrics platform and is described according to the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) checklist.[26] The University of Auckland Human Participants Ethics Committee granted ethics approval for the research on 22 July 2022 for a three-year period (reference number UAHPEC 24713).

Sample

Inclusion criteria included young people who were aged between 16–24 years inclusive, living in Aotearoa, able to read and write in English and had access to the internet and an electronic device to complete the questionnaire.

Procedure

Participants were recruited through the distribution of flyers and emails to secondary schools and universities. Those interested in the study could either enter the website link to gain access to the questionnaire or scan the QR code. Participants could only enter the questionnaire when they had read or downloaded the Participants Information Sheet and Consent Form and answered "agree" to the question "do you agree to take part in this survey?" The questionnaire was anonymous; no names or personal information were collected. The survey did not contain any randomised questions, and participants were allowed to go back and edit their responses before submitting the survey. At the completion of the questionnaire, participants had the option to enter a prize draw. Entries into the prize draw were not linked to the survey response and were stored separately from the questionnaire data.

Survey design

The survey instrument was developed by the research team based on a review of existing EC-related literature and measures. It consisted of 28 questions assessing participants' knowledge and practices regarding EC use and perceptions of the effects of vaping on oral health. The survey instrument consisted of six sections, each displayed on a separate page: demographics (three items), current vaping practices (five items), knowledge of EC products and their health risk (six items), EC and its oral health risks (six items), current oral health status (four items) and willingness to learn more about ECs' health risks (four items). No pre-validated scales were used, as none were deemed appropriate for this context. The questionnaire was pre-tested by researchers before being finalised. Adaptive questioning was used where appropriate to minimise the response burden. The questionnaire is available as Appendix 1.

Analysis

Questionnaire data were analysed and summarised using Excel and Statistical Package for the Social Sciences (IBM SPSS Statistics V.26) software. Survey data were analysed and summarised using descriptive quantitative analyses. Only questionnaires with 75% of the questions completed were included in the final sample. No time limit on the completion of the questionnaire was imposed, IP address information was not recorded and cookies were not used to assign identifiers to each computer. Completeness checks were completed after submission.

Results

Participants' characteristics

Of the 261 people who accessed the survey and consented to participate, 24 responses were excluded due to failure to meet the completion criteria. The total number of complete responses was 237 (completion rate = 90.8%). The total sample included 125 females (52.7%), and most participants (77.6%) identified themselves as European. Table 1 below shows the characteristics of the sample.

Vaping status

Our sample included those who had never vaped (never-users, n=69, 29.1%), those that do not currently vape but have in the past (ever-users, n=87, 36.7%) and current vapers (current-users, n=81, 34.2%). Participants who had previously vaped (ever-users) or who were currently vaping (current-users; n=168) were asked to identify where they obtained their vaping supplies. "Friends and family" were the most common source (n=148, 88.1%). A smaller proportion of participants reported obtaining supplies from physical (n=77, 32.5%) or online stores (n=28, 11.8%). Although it is illegal to sell vaping products to people under the age of 18 years, of the 106 participants who were current or ever-users and below the legal age (under 18 years at the time of the survey), 23.6% (n=25) reported purchasing their vapes from physical or online stores.

The majority of (ever and current) vapers (n=168) in our sample started vaping before the age of 18 years (n=149; 88.7%). The majority (n=108; 64.3%) stated that they started vaping due to curiosity and wanted to know what vaping felt like, and 48.8% (n=82) reported starting as a result of being influenced by friends and family.

General health risk perceptions of vaping

Participants were asked to select how much they agreed or disagreed with questions related to their perceptions of the health risks of vaping on a Likert scale from 1 (strongly disagree) to 5 (strongly agree; Table 2). Approximately two-thirds of participants agreed that vaping was just as addictive as tobacco smoking and that vape juice (e-liquids) may cause long-term health problems (65% and 68%, respectively), and less than half (42.2%) believed vaping to be safer than smoking.

Participants' perception of whether vaping is as addictive as tobacco smoking was not significantly associated with their current vaping status, X2 (2, n=237) = 3.51, p=.173. Current users were significantly more likely to agree that vaping is safer than smoking than ever and non-users, X2 (2, N=237) =10.93, p=.004. Current users were also significantly less likely to agree that vape juice contains chemicals that could cause long-term health issues than ever and non-users (X2 (2, N=237) =19.22, p<.001).

Participants were asked to rate the addictiveness of vaping on a scale from 1 (not at all addictive) to 5 (extremely addictive), with a mean rating 3.7 (SD=1.2). The rating of vaping addictiveness was significantly higher in never-users (M=4.04, SD= 0.99) compared to ever-users (M=3.56, SD=1.30) and current-users (M=3.51, SD=1.19; F [2, 234] =4.60, p=.011).

The harmfulness of vaping was rated on a scale of 1 (not at all harmful) to 5 (extremely harmful) by participants, with a mean rating of 3.6 (SD=1.0). The ratings of the harmfulness of vaping were significantly lower in current-users (M=3.15, SD=1.05) than ever-users (M=3.71, SD=0.99), and never-users (M=3.94, SD=0.80; F [2, 234] =13.92, p<.001).

Participants were also asked to select the body parts that could be adversely affected by vape use; 96.9% (n=229) selected the lungs, 58.6% (n=139) selected the brain, 55.7% (n=132) selected the heart and 51.4% (n=122) selected the mouth. Only 5 (2.1%) respondents indicated they did not believe vaping would affect any of the listed body parts. All five of these participants were current vapers.

Oral health risk perceptions of vaping

Participants were asked to identify what they perceived as the oral health risks of vaping (Table 3). The perceived risk to oral health most frequently identified by participants was dry mouth (64.1%).

Current oral health status and openness for health information on vaping

Participants were asked to rate their general oral health from 1 (extremely unhealthy) to 5 (extremely healthy)—the mean rating was 3.9 (SD=0.9). On average, participants rated their oral health as important (1=not at all important, 5=extremely important; mean rating=4.2, SD=0.9). The majority of participants (n=177; 74.7%) had visited a dental clinic within the past year for an examination or treatment. Only five participants (2.1%) had never had a prior examination or treatment. Only 11.7% of participants (n=27) reported that they had been asked about their vaping status when visiting an oral health professional.

In respect to the provision of information about

Table 1: Participant characteristics (n=237).

Characteristic	N	%
Age group		
16–17 years	156	65.8
18–24 years	81	32.4
Gender		
Female	125	52.7
Male	96	40.5
Another gender	12	5.1
Prefer not to say	4	1.7
Ethnicity		
European	184	77.6
Māori	50	21.1
Pacific Peoples	10	4.2
Asian	33	13.9
Middle Eastern, Latin American and African	3	1.3

Table 2: Participants' level of agreement or disagreement on general health risks of vaping (n=237).

Statements	n (%)		
	Disagree (rating 1 or 2)	Neither (rating 3)	Agree (rating 4 or 5)
Vaping is as addictive as smoking a cigarette	46 (19.4)	38 (16.0)	153 (64.5)
Vaping is safer than smoking a cigarette	48 (20.3)	89 (37.6)	100 (42.2)
Vape juice may cause long-term health problems	25 (10.5)	51 (21.5)	161 (68.0)

Table 3: Participants' perceptions of vaping's oral health risks (n=237).

	n (%)		
Oral health risks	**Yes**	**No**	**Unsure**
Tooth decay	115 (48.5)	35 (14.8)	87 (36.7)
Gum disease	119 (50.2)	30 (12.7)	88 (37.1)
Teeth staining	130 (54.9)	39 (16.5)	68 (28.7)
Dry mouth	152 (64.1)	21 (8.9)	64 (27.0)
Bad breath	113 (47.7)	62 (26.2)	62 (26.2)
Oral cancer	113 (47.7)	38 (16.0)	86 (36.3)

vaping on oral health, the majority (n=217; 93.9%) of participants had never asked their oral health professionals for EC-related health information. However, the majority (n=180; 76.0%) indicated that they would be happy to receive vaping-related health information from healthcare providers. Over half (n=130; 54.9%) reported they would prefer to acquire this type of information from social media platforms; 46.8% (n=111) would prefer to receive health information from their school or workplaces.

Overall, participants were moderately willing to discuss vaping with an oral health professional (mean rating=3.5, SD=1.1; 1=not at all willing, 5=extremely willing). Compared to current-users, non-current users (ever and never users) were more likely to agree that they would be less likely to vape if they believed vaping was detrimental to oral health, X2 (2, N=230) =32.07, p<.001.

Discussion

This study was designed to provide a snapshot of young people's perceptions of the risks of vaping on oral health in Aotearoa. Results confirm that the majority of young people surveyed perceive vaping to be addictive and harmful to their general health. However, between groups' analyses reveal interesting discrepancies. Current users tended to have significantly lower perceptions of the health risks and addictiveness of vaping compared to ever or never users. This group were less likely to agree that vape liquid contains chemicals that could cause long-term health issues.

Comparisons with tobacco were consistent with international studies. Vaping is widely perceived to pose health risks, but is inherently safer than smoking tobacco.[24,27–31] The perception that vaping is safer is not surprising, given recent campaigns targeting smokers to "make the switch" to vaping. Until recently, the marketing of vape products has been largely unregulated, allowing retailers and the industry to capitalise on social media and others' media to promote sales. Young people have been heavily targeted in campaigns aimed not only at promoting people to switch to a safer product but to vape for lifestyle and social conformity or mental health reasons.

The majority of participants reported that vaping could negatively impact their lungs, demonstrating that young people have some appreciation of the risks of vaping. In the wake of the e-cigarette or vaping use-associated lung injury (EVALI) and COVID-19 outbreaks, there has been a heightened awareness of the respiratory risks associated with ECs, which may explain these findings.[32–34] In contrast, perception of oral health effects of vaping was generally low. Our sample reported dry mouth followed by teeth staining as associated with vaping, compared to other risks such as oral cancers.

Moreover, vaping information was not consistently provided or sought from oral health professionals. This study has highlighted the potential need for wider dissemination of public health information demonstrating the potential harmful effects of EC use generally, and as the evidence becomes available, on oral health. Oral health professionals rarely communicate to young people the risk of vaping. Previous research also found that most dental professionals fail to enquire about their patients' vaping status.[37] Martell and colleagues,[23] identified that if participants knew vaping was detrimental to oral health, this may influence their uptake. Our study found that young people would be happy to receive health information on vaping from their healthcare professionals, including oral health professionals.[35,37]

The current study provides the first glimpse into perceptions of oral health risks of vaping in Aotearoa, but it is not without limitations. Firstly, although the survey was anonymous, there is potential for social desirability bias. It is possible that participants did not reveal all of their experiences or altered them to reflect what they felt comfortable sharing. Further, respondents with preconceived opinions or prejudices may self-select into the sample.[37] The generalisability of the results is also limited by an underrepresentation of Pacific peoples and gender-diverse communities.

It is clear that healthcare professionals, especially oral health professionals, are ideally positioned to actively engage in counselling and recording their patients' vaping status. Oral health professionals have a unique opportunity to provide health information about vaping to their patients. There are also opportunities for curriculum design to facilitate the future healthcare workforce with a better understanding of vaping's health risks and support to provide evidence-based health information and cessation strategies.[38,39]

The study findings also have implications for wider policy and regulation of ECs to prevent uptake among non-smokers and young people and prevent potential oral health harm. Vaping policies and regulations in Aotearoa could consider a precautionary principle, which emphasises the scientific uncertainty about the long-term health consequences of vaping and focusses on regulations that prohibit or reduce it. *As the Smokefree Environments and Regulated Products (Smoked Tobacco) Amendment Bill*[4] bans the sale of tobacco to a "smokefree generation" born after January 1, 2009, the government could also take action to prevent our young people from starting vaping.

Conclusion

This study investigated young people's perceptions of the general and oral health risks of vaping in Aotearoa. Despite the study's limitations, the findings provide valuable insights that can inform future research and policy as more conclusive evidence of the potential health risks of vaping becomes available. The results showed that the majority of young people surveyed perceive vaping to be addictive and harmful to their general health, but their perceptions of the oral health effects of vaping were generally low. Although the current evidence for the health risks of vaping, in particular the oral health risks, is still inconclusive, it is essential that we continue to seek input from young people on factors that underpin decision-making around vaping.

COMPETING INTERESTS

Nil.

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REFERENCES

1. Besaratinia A, Tommasi S. Vaping: A growing global health concern. EClinicalMedicine. 2019 Nov 16;17:100208. doi: 10.1016/j.eclinm.2019.10.019.
2. Ball J, Crossin R, Boden JM, et al. Long-term trends in adolescent alcohol, tobacco and cannabis use and emerging substance use issues in Aotearoa New Zealand. J R Soc N Z. 2022 Apr;52(1510):1-22. doi: 10.1080/03036758.2022.2060266.
3. Manatū Hauora – Ministry of Health. Annual Update of Key Results 2021/22: New Zealand Health Survey [Internet]. Wellington: Manatū Hauora – Ministry of Health; 2022 Nov [cited 20 Feb 2023]. Available from: https://www.health.govt.nz/publication/annual-update-key-results-2021-22-new-zealand-health-survey.
4. New Zealand Parliament. Smokefree Environments and Regulated Products (Smoked Tobacco) Amendment Bill [Internet]. Wellington: New Zealand Parliament; 2022 [cited 16 Feb 2023]. Available from: https://www.parliament.nz/en/pb/bills-and-laws/bills-proposed-laws/document/BILL_125245/smokefree-environments-and-regulated-products-smoked-tobacco.
5. Rouabhia M. Impact of electronic cigarettes on oral health: a review. J Can Dent Assoc. 2020 Mar;86:k7:1488-2159.
6. Sultan AS, Jessri M, Farah CS. Electronic nicotine delivery systems: Oral health implications and oral cancer risk. J Oral Pathol Med. 2021 Mar;50(3):316-322. doi: 10.1111/jop.12810.
7. Hasana NWM, Baharina B, Mohda N. Electronic Cigarette Vapour and the Impacts on Oral Health: A Review. Arch Orofac Sci. 2022 Aug;17(Suppl 1):1-9. doi: 10.21315/aos2022.17S1.RV01.
8. Wilson C, Tellez Freitas CM, Awan KH, et al. Adverse effects of E-cigarettes on head, neck, and oral cells: A systematic review. J Oral Pathol Med. 2022 Feb;51(2):113-125. doi: 10.1111/jop.13273.
9. Irusa KF, Vence B, Donovan T. Potential oral health effects of e-cigarettes and vaping: A review and case reports. J Esthet Restor Dent. 2020 Apr;32(3):260-264. doi: 10.1111/jerd.12583.
10. Pushalkar S, Paul B, Li Q, et al. Electronic cigarette aerosol modulates the oral microbiome and increases risk of infection. iScience. 2020 Mar 27;23(3):100884. doi: 10.1016/j.isci.2020.100884.
11. Holliday R, Chaffee BW, Jakubovics NS, et al. Electronic Cigarettes and Oral Health. J Dent Res. 2021 Aug;100(9):906-913. doi: 10.1177/00220345211002116.
12. Atuegwu NC, Perez MF, Oncken C, et al. Association between regular electronic nicotine product use and self-reported periodontal disease status: population assessment of tobacco and health survey. Int J Environ Res Public Health. 2019 Apr 9;16(7):1263. doi: 10.3390/ijerph16071263.
13. Cho JH. The association between electronic-cigarette use and self-reported oral symptoms including cracked or broken teeth and tongue and/or inside-cheek pain among adolescents: A cross-sectional study. PloS one. 2017 Jul 11;12(7):e0180506. doi: 10.1371/journal.pone.0180506.
14. Yang I, Sandeep S, Rodriguez J. The oral health impact of electronic cigarette use: a systematic review. Crit Rev Toxicol. 2020 Feb;50(2):97-127. doi: 10.1080/10408444.2020.1713726.
15. Ismail AF, Ghazali AF. Electronic cigarettes and oral health: A narrative review. Int J Pharm Res. 2018 Apr;10(2):84-86.
16. Hardie L, McCool J, Freeman B. Online retail promotion of e-cigarettes in New Zealand: A content analysis of e-cigarette retailers in a regulatory void. Health Promot J Austr. 2022 Jan;33(1):91-98. doi: 10.1002/hpja.464.
17. Hardie L, McCool J, Freeman B. E-Cigarette Retailers' Use of Instagram in New Zealand: A Content Analysis. Int J Environ Res Public Health. 2023 Jan 19;20(3):1897. doi: 10.3390/ijerph20031897.
18. Bouttier-Esprit T, Dobson R, Saxton P, McCool J.

Use of e-cigarettes among young queer men living in Aotearoa New Zealand. J Prim Health Care. 2023 Jun;15(2):172-175. doi: 10.1071/HC22154.

19. Cochran C, Robertson L, Hoek J. Online marketing activity following New Zealand's vaping legislation. Tob Control. 2023 Mar;32(2):263-264. doi: 10.1136/tobaccocontrol-2021-056750.
20. Young-Wolff KC, Klebaner D, Folck B, et al. Do you vape? Leveraging electronic health records to assess clinician documentation of electronic nicotine delivery system use among adolescents and adults. Prev Med. 2017 Dec;105:32-36. doi: 10.1016/j.ypmed.2017.08.009.
21. Winden TJ, Chen ES, Wang Y, et al. Towards the standardized documentation of e-cigarette use in the electronic health record for population health surveillance and research. AMIA Jt Summits Transl Sci Proc. 2015 Mar 25;2015:199-203.
22. Hurst S, Conway M. Exploring Physician Attitudes Regarding Electronic Documentation of E-cigarette Use: A Qualitative Study. Tob Use Insights. 2018 Jul 20;11:1179173X18782879. doi: 10.1177/1179173X18782879.
23. Martell KM, Boyd LD, Giblin-Scanlon LJ, Vineyard J. Knowledge, attitudes, and practices of young adults regarding the impact of electronic cigarette use on oral health. J Am Dent Assoc. 2020 Dec;151(12):903-911. doi: 10.1016/j.adaj.2020.08.002.
24. McKelvey K, Baiocchi M, Halpern-Felsher B. Adolescents' and young adults' use and perceptions of pod-based electronic cigarettes. JAMA Netw Open. 2018 Oct 5;1(6):e183535. doi: 10.1001/jamanetworkopen.2018.3535.
25. Burnley A, Bold KW, Kong G, et al. E-cigarette use perceptions that differentiate e-cigarette susceptibility and use among high school students. Am J Drug Alcohol Abuse. 2021 Mar 4;47(2):238-246. doi: 10.1080/00952990.2020.1826501.
26. Eysenbach G. Improving the quality of Web surveys: the Checklist for Reporting Results of Internet E-Surveys (CHERRIES). J Med Internet Res. 2004 Sep 29;6(3):e132. doi: 10.2196/jmir.6.3.e34.
27. Aqeeli AA, Makeen AM, Al Bahhawi T, et al. Awareness, knowledge and perception of electronic cigarettes among undergraduate students in Jazan Region, Saudi Arabia. Health Soc Care Community. 2022 Feb;30(2):706-713. doi: 10.1111/hsc.13184.
28. Russell C, Katsampouris E, Mckeganey N. Harm and addiction perceptions of the JUUL e-cigarette among adolescents. Nicotine Tob Res. 2020 Apr 21;22(5):713-721. doi: 10.1093/ntr/ntz183.
29. Al-Sawalha NA, Almomani BA, Mokhemer E, et al. E-cigarettes use among university students in Jordan: Perception and related knowledge. PLoS One. 2021 Dec 31;16(12):e0262090. doi: 10.1371/journal.pone.0262090.
30. Vogel EA, Henriksen L, Schleicher NC, Prochaska JJ. Young people's e-cigarette risk perceptions, policy attitudes, and past-month nicotine vaping in 30 US cities. Drug Alcohol Depend. 2021 Dec 1;229(Pt A):109122. doi: 10.1016/j.drugalcdep.2021.109122.
31. Khader H. Use and beliefs about e-cigarette among college students in Jordan. J Med J. 2020;54(2):89-98.
32. East K, Reid JL, Burkhalter R, et al. Exposure to Negative News Stories About Vaping, and Harm Perceptions of Vaping, Among Youth in England, Canada, and the United States Before and After the Outbreak of E-cigarette or Vaping-Associated Lung Injury ('EVALI'). Nicotine Tob Res. 2022 Aug 6;24(9):1386-1395. doi: 10.1093/ntr/ntac088.
33. Jun J, Fitzpatrick MA, Zain A, Zhang N. Have E-cigarette Risk Perception and Cessation Intent of Young Adult Users Changed During the Pandemic? Am J Health Behav. 2022 Jun 23;46(3):304-314. doi: 10.5993/AJHB.46.3.9.
34. Wagoner KG, King JL, Alexander A, et al. Adolescent Use and Perceptions of JUUL and Other Pod-Style e-Cigarettes: A Qualitative Study to Inform Prevention. Int J Environ Res Public Health. 2021 May 1;18(9):4843. doi: 10.3390/ijerph18094843.
35. Drouin O, McMillen RC, Klein JD, Winickoff JP. E-cigarette advice to patients from physicians and dentists in the United States. Am J Health Promot. 2018 Jun;32(5):1228-1233. doi: 10.1177/0890117117710876.
36. Chaffee BW, Urata J, Couch ET, Silverstein S. Dental professionals' engagement in tobacco, electronic cigarette, and cannabis patient counseling. JDR Clin Trans Res. 2020 Apr;5(2):133-145. doi: 10.1177/2380084419861384.
37. Andrade C. The limitations of online surveys. Indian J Psychol Med. 2020 Oct 13;42(6):575-576. doi: 10.1177/0253717620957496.
38. Mungia R, Case K, Valerio MA, et al. Development of an E-cigarettes education and cessation program: a South Texas oral health network study. Health Promot Pract. 2021 Jan;22(1):18-20. doi: 10.1177/1524839920914870.
39. Martín Carreras-Presas C, Naeim M, Hsiou D, et al. The need to educate future dental professionals on E-cigarette effects. Eur J Dent Educ. 2018 Nov;22(4):e751-e758. doi: 10.1111/eje.12390.

Appendix 1: Part 1 survey.

Start of block: participant information

Q1.1 Welcome to the survey! This survey will explore your perception and knowledge of vaping and its oral side effects. Here is the Participant Information Sheet for more information on this survey and the study. Please click on the Consent Form if you would like to keep a copy for yourself (you are not required to return the form as this survey is anonymous).

Q1.2 Please click “agree” below if you provide consent to participate:

○ Agree

Start of block: demographics

Q2.1 How old are you?

○ 16–17 years old

○ 18–24 years old

Q2.2 Which ethnic group do you belong to? (Select all that apply)

☐ NZ European

☐ Māori

☐ Samoan

☐ Cook Island Māori

☐ Tongan

☐ Niuean

☐ Chinese

☐ Indian

☐ Other such as Dutch, Japanese, Tokelauan. Please state:

Q2.3 How do you describe yourself?

○ Male

○ Female

○ Another gender

○ Prefer not to say

Start of block: vaping practice

Q3.1 The following questions will ask about your experiences with vaping. Definitions: vaping— refers to the use of an electronic device that heats a liquid, turning it into an aerosol (vapour) which the user inhales.

Appendix 1 (continued): Part 1 survey.

Vaping practice

Q3.2 Have you ever vaped (even just once)?

○ Yes, I currently vape daily
○ Yes, I currently vape at least once a week
○ Yes, I currently vape but less than once a week
○ I used to vape but have quit
○ I have only tried vaping once or twice
○ I have never vaped

Q3.3 Where did/do you get your vape supplies from? (Select all that apply)

☐ From family members
☐ From friends
☐ Online from internet suppliers/stores
☐ From a vape specialty store
☐ From a petrol station
☐ From a dairy
☐ Other (please specify

Q3.4 How old were you when you first start vaping?

○ <14 years old
○ 14–15 years old
○ 16–17 years old
○ >18 years old

Q3.5 When you first tried vaping, what were the reasons for trying? (Select all that apply)

☐ My friends or family members do it
☐ Flavours are good
☐ It's safer than smoking
☐ Wanted to quit smoking
☐ Vaping ads made me want to try it
☐ It's cool
☐ As a way of coping with stress
☐ I wanted to know what it was like
☐ Other (please specify)

Start of block: knowledge on vaping products and its health risk

Q4.1 The following questions will ask about your views on vaping and its health risk. Definition: vape devices—vape devices are also known as e-cigarettes, which are battery-operated devices that people use to inhale an aerosol (vapour from vape juice). Typically, they include a battery, a refillable tank or a disposable vape juice cartridge.

Appendix 1 (continued): Part 1 survey.

Knowledge on vaping products and its health risk
Q4.2 Please indicate how much you agree or disagree with the following statement from 1 (strongly disagree) to 5 (strongly agree): vaping is as addictive as smoking a cigarette: ○ 1 Strongly disagree ○ 2 Disagree ○ 3 Neither agree nor disagree ○ 4 Agree ○ 5 Strongly agree
Q4.3 Please indicate from 1 (not addictive at all) to 5 (extremely addictive) how addictive you believe vaping is: ○ 1 Not addictive at all ○ 2 ○ 3 ○ 4 ○ 5 Extremely addictive
Q4.4 Please indicate how much you agree or disagree with the following statement from 1 (strongly disagree) to 5 (strongly agree): vaping is safer than smoking a cigarette? ○ 1 Strongly disagree ○ 2 Disagree ○ 3 Neither agree nor disagree ○ 4 Agree ○ 5 Strongly agree
Q4.5 How harmful do you think vaping is to a person's physical health? *Physical health—physical health refers to the health of your body. It takes into account everything from the absence of illness to the level of physical fitness. ○ 1 Not harmful at all ○ 2 ○ 3 ○ 4 ○ 5 Extremely harmful

Appendix 1 (continued): Part 1 survey.

Knowledge on vaping products and its health risk

Q4.6 Please indicate how much you agree or disagree with the following statement from 1 (strongly disagree) to 5 (strongly agree): vape juice contains chemicals that may cause long-term health problems: *Vape juice—vape juice is the liquid used in vape devices that gets turned into vapour. It also comes under other names such as e-juice, e-liquid and vape liquid. No matter the size or look of the vaping device, the production of vapour requires the presence of vape juice.

○ 1 Strongly disagree
○ 2 Disagree
○ 3 Neither agree nor disagree
○ 4 Agree
○ 5 Strongly agree

Q4.7 Which of the following parts of body do you think that vaping has a negative impact on: (Select all that apply)

☐ Lung
☐ Heart
☐ Brain
☐ Mouth
☐ None of above

Start of block: vaping and oral health

Q5.1 The following questions will ask about your views on the risks of vaping on oral health.

Q5.2 Do you think vaping can contribute to tooth decay? *Tooth decay—permanently damaged areas in the hard surface of your teeth that develop into tiny openings or holes.

○ Yes
○ No
○ Unsure

Q5.3 Do you think vaping is related to gum disease? *Gum disease—the inflammation of the gums that can go on to destroy the bone surrounding your teeth.

○ Yes
○ No
○ Unsure

Q5.4 Do you think vaping can contribute to teeth staining? *Tooth staining—when the colour of your teeth changes. Teeth may darken, turn from white to different colours, or develop opaque or dark spots in places.

○ Yes
○ No
○ Unsure

Appendix 1 (continued): Part 1 survey.

Vaping and oral health

Q5.5 Do you think vaping can contribute to dry mouth? *Dry mouth—dryness or a feeling of stickiness in your mouth, saliva that seems thick and stringy, dry, or sore throat and hoarseness, dry or grooved tongue.

○ Yes
○ No
○ Unsure

Q5.6 Do you think vaping can contribute to bad breath? *Bad breath—is a persistent, unpleasant odour in exhaled breath.

○ Yes
○ No
○ Unsure

Q5.7 Do you think vaping increases the risk of oral cancer? *Oral cancer—cancers of the mouth including lip cancer, jaw cancer and tongue cancer.

○ Yes
○ No
○ Unsure

Start of block: oral health practice

Q6.1 The following questions will ask about your views on oral health and oral health behaviours.

Q6.2 How would you rate your current oral health on a scale from 1 (very poor) to 5 (extremely healthy)? *Oral health—the health of your teeth, gums and the parts of your face that help you to smile, speak and chew.

○ 1 Very poor
○ 2
○ 3
○ 4
○ 5 Extremely healthy

Q6.3 When was the last time you visited a dental clinic for check-up or treatment?

○ Never been to a dental clinic
○ Last 12 months
○ Last 24 months
○ 2–5 years ago
○ >5 years ago

Appendix 1 (continued): Part 1 survey.

Oral health practice

Q6.4 Have you ever been asked if you vape or not when visiting a dental professional? *Dental professional—a person who has the training or expertise to provide care to your mouth and teeth (such as a dentist, dental hygienist, dental therapist, dental nurse, oral health therapist).

○ Yes
○ No

Q6.5 Have you asked any dental professionals about vaping and oral health?

○ Yes
○ No

Start of block: attitudes and willingness

Q7.1 Please indicate on a scale from 1 (not at all important) to 5 (extremely important) how important is it to you to have good oral health.

○ 1 Not at all important
○ 2
○ 3
○ 4
○ 5 Extremely important

Q7.2 Please indicate how willing you would be to discuss the impact of vaping on oral health with a dental professional on a scale from 1 (not at all willing) to 5 (extremely willing). *Dental professional—a person who has the training or expertise to provide care to your mouth and teeth (such as a dentist, dental hygienist, dental therapist, dental nurse, oral health therapist).

○ 1 Not willing at all
○ 2
○ 3
○ 4
○ 5 Extremely willing

Q7.3 Please indicate how much you agree or disagree with the following statement from 1 (strongly disagree) to 5 (strongly agree): I would be less likely to vape if I believed it was harmful to my oral health.

○ 1 Strongly disagree
○ 2 Disagree
○ 3 Neither agree nor disagree
○ 4 Agree
○ 5 Strongly agree

Appendix 1 (continued): Part 1 survey.

Attitudes and willingness

Q7.4 Which of the following sources would you be happy to receive information on the health effects of vaping from: (Select all that apply)

☐ Healthcare providers (such as GPs, nurses, oral health professionals, pharmacists, etc.)
☐ Social media (such as Instagram, TikTok, etc.)
☐ School/university/workplaces
☐ Other (please specify)

Start of block: end of survey

Q8.1 Please click “submit” below if you are ready. You will then be taken to a page where you can enter the prize draw and/or request a copy of the study results. Please be aware that once you submit your survey, you cannot withdraw from this study.

○ Submit

Q8.2 Would you like to enter a prize draw for an Apple Airpods Pro or an Oral-B Genius 9000 Toothbrush? Your survey response still remains anonymous.

○ Yes
○ No

End of block: end of survey

Non-attendance at diabetic retinal screening in Te Tai Tokerau, Northland, Aotearoa New Zealand

Laura E Wolpert, Christopher HJA Sadler, Andrew R Watts, David M Dalziel

ABSTRACT

AIMS: To explore socio-demographic characteristics of non-attenders at diabetic retinal screening.

METHODS: A retrospective, register-based cross-sectional analysis of 10,275 participants invited to diabetic retinal screening in Te Tai Tokerau (Northland) between May 2011 and June 2020 was performed. Multivariable logistic regression analysis was used to assess the association of age, sex, type of diabetes, ethnicity and socio-economic deprivation with non-attendance at diabetic retinal screening.

RESULTS: Median age was 66 years and 54.3% of participants were male. The non-attendance rate was 26.4%, with 46.6% of individuals having at least one non-attendance. Younger age was associated with higher odds of non-attendance (OR 1.84 95% CI 1.41–2.40, $p<0.001$ for odds of non-attendance in those aged under 35 years compared with age over 75 years). Māori (OR 2.69, 95% CI 2.44–2.96, $p<0.001$) and Pacific peoples (OR 1.71, 95% CI 1.25–2.36, $p=0.001$) had higher odds of non-attendance compared with NZ Europeans. People living in areas of high socio-economic deprivation had higher odds of non-attendance (OR 1.56, 95% CI 1.33–1.82, $p<0.001$), as did type 1 diabetics (OR 1.31, p5% CI 1.08–1.59, $p=0.006$).

CONCLUSION: Younger age, socio-economic deprivation, type 1 diabetes and Māori and Pacific ethnicity are risk factors for non-attendance at diabetic retinal screening.

Diabetic retinopathy is a leading cause of visual impairment and blindness among working-age adults in high-income countries, with an increasing age-standardised prevalence globally.[1] Loss of vision may be avoided through early evaluation of retinopathy via screening, prompting timely referral for assessment and intervention by an ophthalmologist.[2] Repeated non-attendance at diabetic retinal screening is a risk factor for sight-threatening retinopathy.[3] As of 2019 there were over 260,000 New Zealanders suspected of having diabetes, with 11,625 living in Te Tai Tokerau (Northland).[4] Te Tai Tokerau is one of the most highly socio-economically deprived regions in Aotearoa New Zealand, with the 2018 New Zealand Index of Deprivation classifying 23.2% of households in Te Tai Tokerau as being in the highest socio-economic deprivation decile.[5]

A number of Aotearoa New Zealand-based studies have examined rates of non-attendance by ethnicity, finding Māori and Pacific peoples to have higher rates of non-attendance at screening compared with NZ Europeans. However, most previous studies did not disaggregate non-attendance rates by other possible risk factors, including age, sex, type of diabetes or socio-economic deprivation.[6–9] Studies from overseas have shown that those of younger age[10–13] and those who are more socio-economically deprived[11–14] have lower access to screening; however, to date there have been no comprehensive studies in Aotearoa New Zealand on the socio-demographic characteristics of non-attenders at diabetic retinal screening clinics. Several measures have been taken to increase access to screening in Te Tai Tokerau, including the use of 23 hospital and community-based sites based across the region to reduce travel distance to appointments, and the use of telephone appointment reminders. Understanding risk factors for reduced access to diabetic retinal screening is crucial for identifying strategies to increase screening uptake. This study explores socio-demographic characteristics of non-attendance at diabetic retinal screening in Te Tai Tokerau, Aotearoa New Zealand, to inform improvements in service design.

Methods

A retrospective, register-based cross-sectional analysis of participants invited to diabetic retinal screening in Te Tai Tokerau between 31 May 2011 and 17 June 2020 was performed. All individuals invited to attend for screening in Te Tai Tokerau were eligible for inclusion in the study. In accordance with national guidelines, all adults with newly diagnosed type 2 diabetes are invited to screening in Te Tai Tokerau, as are all people with newly diagnosed type 1 diabetes either within 5 years of diagnosis, or when they reach the age of 10, whichever comes first.[15] Participants are screened biennially across 23 hospital-based and community-based sites (Figure 1). Data are stored in the Ophthalmology Digital Healthcare Database. This study received approval from Northland District Health Board. Formal ethics approval was not sought on the basis of this study being an audit of routinely collected data, in line with the Health and Disability Ethics Committee (HDEC) guidance.

Data were collected by a pre-screening questionnaire and entered into the database by a trained nurse. Variables included in analyses were age, sex, self-reported ethnicity coded according to Manatū Hauora – Ministry of Health's Ethnicity Data Protocols,[16] and socio-economic deprivation. Socio-economic deprivation was assessed using the New Zealand Index of Deprivation (NZDep), which was obtained from participants' postcodes. The NZDep measures level of socio-economic deprivation for people living within an area based on Census data from 2018. The NZDep is divided into deciles, with decile 1 representing the least socio-economically deprived 10% of small areas and decile 10 the most socio-economically deprived 10%.[17] Due to issues of data scarcity, for the purpose of this study three socio-economic deprivation level categories were created: "low socio-economic deprivation" represented individuals in deciles 1–4, "medium socio-economic deprivation" represented deciles 5–8 and "high socio-economic deprivation" included those in deciles 9 and 10. Appointments were recorded as either attended or not attended. Non-attendance was defined as a patient not attending for an invited appointment without prior notice being given, with cancellations or rescheduled appointments not classified as a non-attendance, in keeping with the definition used by Leese et al.[11] The overall non-attendance rate by appointment was calculated. For the multivariable analysis, non-attendance was classified as an individual not attending at least one scheduled appointment during the study period.

Baseline characteristics were investigated, with Chi-squared tests used to examine the association of categorical covariates with non-attendance. Multivariable logistic regression was used to determine the association of non-attendance at diabetic retinal screening with age, sex, ethnicity, socio-economic deprivation and type of diabetes. Missing data were less than 5% for each variable and data were determined to be missing completely at random; thus, in both univariate and multivariate analysis, complete case analysis was used. Statistical analyses were performed using Stata/BE 18.0.

Results

In total, 10,275 people were invited to a total of 41,942 diabetic retinal screening appointments in Te Tai Tokerau during the study period. Of these participants, 54.3% were male (n=5,575). Median age was 65.7 years (range 8 to 100 years). NZ European (52.3%) and Māori (42.5%) were the most prevalent ethnic groups. Median age was 70 years for NZ Europeans, 61 years for Māori and 56 for Pacific Peoples. Thirty-eight point six percent (n=2,045) of NZ Europeans lived in the most deprived quintile compared with 70.9% (n=3,054) of Māori and 65.4% (n=138) of Pacific peoples ($p<0.001$ from Chi-squared test). Type 2 diabetics accounted for 93.5% of the study population. The baseline study distribution is described in Table 1.

The overall non-attendance rate was 26.4% (n=11,059). Forty-seven percent of invitees to retinal screening did not attend for at least one appointment (n=4,827). The median number of non-attendances per participant who had at least one non-attendance was 2 (IQR 1–3). In the univariate analysis, female sex was associated with an increased odds of non-attendance at screening (OR 1.09, 95% CI 1.00–1.17). There was a trend for increased non-attendance at diabetic retinal screening with decreasing age (p-value for trend <0.001). Non-attendance was highest in those aged 35 years and under (59.4%) and lowest in those aged older than 75 years (34.4%). Compared to NZ Europeans, Māori (OR 3.16, 95% CI 2.89–3.44) and Pacific people (OR 2.61, 95% CI 1.97–3.45) experienced lower access to diabetic retinal screening. There was a trend for increasing odds of non-attendance with increasing socio-economic deprivation ($p<0.001$), with 53.2% of those in the most deprived group not attending screening compared with 34.0% in the least deprived group (OR 2.21, 95% CI 1.91–2.55). Table 1 displays the results from the univariate analysis.

Following multivariable logistic regression, sex was no longer associated with an increased odds of non-attendance (OR 1.02, 95% CI 0.94–

1.11, p=0.67). Younger age remained associated with increased odds of non-attendance, with those under age 35 years having a higher odds of non-attendance compared with those age over 75 years (OR 1.76, 95% CI 1.37–2.27, p<0.001). Compared to NZ Europeans, Māori (OR 2.72, 95% CI 2.48–2.99, p<0.001) and Pacific people (OR 1.81, 95% CI 1.33–2.47, p<0.001) had higher odds of non-attendance. There was a trend for increasing odds of non-attendance with higher socio-economic deprivation (p<0.001). Type 1 diabetes was also a risk factor for non-attendance (OR 1.31, 95% CI 1.09–1.58, p=0.005). Table 2 shows the association of risk factors with non-attendance at screening in the multivariable analysis.

Discussion

This cross-sectional study found a high rate of non-attendance at diabetic retinal screening, with around one in four screening appointments not attended, and almost half of individuals not attending at least one invited appointment. This study found that risk factors for non-attendance at diabetic retinal screening were younger age groups, type 1 diabetics, people of Māori and Pacific ethnicity and people living in areas of high socio-economic deprivation.

The overall non-attendance rate of 26.4% was higher than the non-attendance rate of 12.9% observed in a study on non-attendance at first retinal screening appointment in Wellington by Chang et al.[8] In the Chang study, both Māori and Pacific peoples had higher rates of non-attendance (31.7% and 44.0% respectively) compared with NZ Europeans, and so the lower overall attendance rate observed in this study may be due to the lower proportion of Māori and Pacific peoples in the Wellington diabetic retinal screening population (13.0% and 10.5% respectively). In a cross-sectional study in the Waikato, Lawrenson et al. found that 36.3% of patients with diabetes enrolled across three general practices had no record of screening over a 2-year period.[9] In another Waikato-based

Figure 1: Map showing location of diabetic retinal screening clinics in Te Tai Tokerau region.

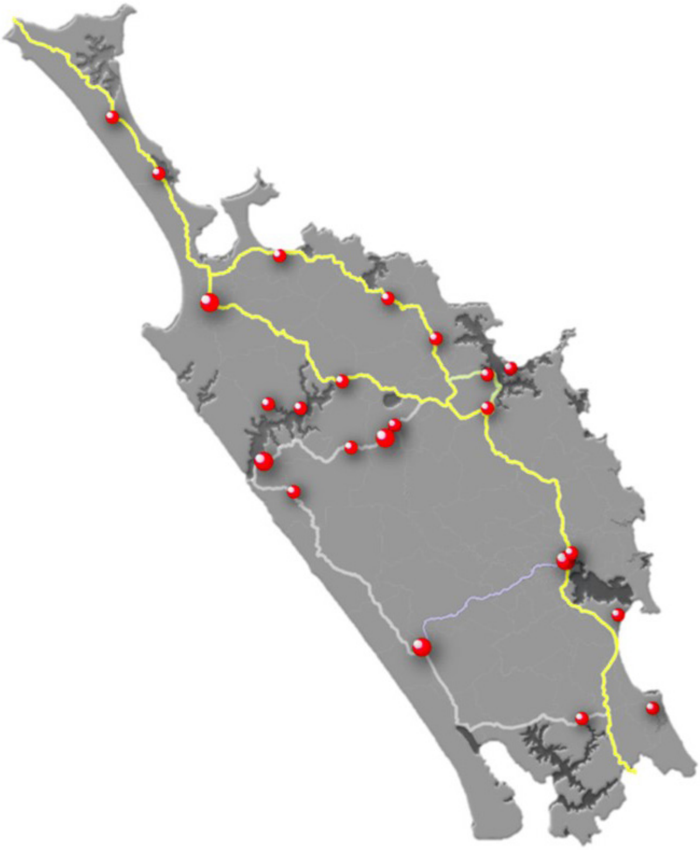

Table 1: Baseline distribution of people with diabetes in Te Tai Tokerau invited to attend retinal screening, May 2011–June 2020.

	Total number (col%)	Number of non-attenders (row%)	OR (95% CI) for non-attendance	p-value
Age (years)				
<35	411 (4.0)	244 (59.4)	2.79 (2.24–3.46)	
35–54	2,004 (19.5)	1,148 (57.3)	2.56 (2.26–2.90)	
55–74	5,412 (52.7)	2,593 (47.9)	1.75 (1.59–1.94)	
>75	2,448 (23.8)	842 (34.4)	1	<0.001*
Sex				
Male	5,575 (54.3)	2,569 (46.1)	1	
Female	4,689 (45.7)	2,257 (48.1)	1.09 (1.00–1.17)	0.038*
Ethnicity				
NZ European	5,311 (52.3)	1,829 (34.4)	1	
Māori	4,319 (42.5)	2,694 (62.4)	3.16 (2.89–3.44)	
Pacific peoples	211 (2.1)	122 (57.8)	2.61 (1.97–3.45)	
Asian	259 (2.6)	108 (41.7)	1.36 (1.06–1.75)	
Other	62 (0.6)	22 (35.5)	1.05 (0.62–1.77)	<0.001*
Socio-economic deprivation				
Low	948 (9.3)	322 (34.0)	1	
Medium	3,861 (37.7)	1,603 (41.5)	1.38 (1.19–1.60)	
High	5,436 (53.1)	2,889 (53.2)	2.21 (1.91–2.55)	<0.001*
Diabetes				
Type 1	618 (6.5)	297 (48.1)	1.18 (1.01–1.39)	
Type 2	8,941 (93.5)	3,923 (43.9)	1	0.04

*Significant p-values from Chi-squared tests.

Table 2: Factors associated with non-attendance at diabetic retinal screening in a multivariable model.

	OR (95% CI) for non-attendance	p-value
Age (years)		
<35	1.76 (1.37–2.72)	
35–54	1.60 (1.40–1.84))	
55–74	1.41 (1.27–1.57)	
>75	1	<0.001
Sex		
Male	1	
Female	1.02 (0.94–1.11)	0.67
Ethnicity		
NZ European	1	
Māori	2.72 (2.48–2.99)	<0.001
Pacific peoples	1.81 (1.33–2.47)	<0.001
Asian	1.30 (1.00–1.70)	0.054
Other	1.03 (0.60–1.77)	0.9
Socio-economic deprivation		
Low	1	
Medium	1.34 (1.15–1.58)	
High	1.55 (1.32–1.81)	<0.001
Type of diabetes		
Type 1	1.31 (1.09–1.58)	
Type 2	1	0.005

study of participants invited to attend retinal screening in the Waikato Mobile Diabetic Retinopathy Photoscreening Programme, the overall non-attendance rate was 18.7%, slightly lower than the non-attendance rate observed in the current study.[18]

This study did not find sex to be associated with non-attendance at retinal screening, in keeping with findings from previous studies from abroad.[10,11,19] Younger age was associated with lower uptake of retinal screening, with participants aged under 35 years having 76% higher odds of non-attendance compared with those over 75 years. Lower screening uptake in younger age groups has been has been reported in other studies from overseas.[10–13] Lawrenson et al.[12] reported lower attendance rates in adults aged 24–29, and a study on factors determining uptake of retinal screening in Oxfordshire by Moreton et al. also found higher non-attendance in people aged under 35, with approximately a third of this group not taking up their appointment.[10] A cross-sectional study on socio-economic and ethnic disparities in diabetic retinal screening in South London also showed about a third of people age 18–34 did not attend for diabetic retinal screening.[13] Reduced uptake of screening in younger age groups is of concern, as younger people have be shown to have higher rates of referrable retinopathy at first screen in a cross-sectional study in the UK.[20] Younger people may face unique obstacles to retinal screening. A qualitative study on factors affecting uptake of retinal screening in young adults with type 2 diabetes in Australia by Lake et al.[21] highlighted several barriers that had more salience for younger adults compared with older adults. These included low perceived risk of diabetic retinopathy, or, conversely, fear of vision loss, or of losing the ability to drive. Simmons et al.[22] described personal financial issues and emotional barriers to care, such as fear, shame and anxiety, to be more prevalent in younger persons with diabetes. Lake et al. also highlighted several positive facilitators in accessing retinal screening. These included factors such as social influence, with participants stating that reinforcement from healthcare professionals such as GPs, and from friends and family, understanding of the importance of screening, and a feeling of satisfaction if screening was normal, as this suggested good diabetic control, encouraged retinal screening attendance.[21]

This study found Pacific peoples and Māori to have reduced access to diabetic retinal screening compared with NZ Europeans after controlling for confounders, with over half of Māori and Pacific people not attending at least one screening appointment during the study period. The finding of reduced access to retinal screening in Māori and Pacific people is in keeping with a systematic review of diabetic retinal screening non-attendance by ethnicity in Aotearoa New Zealand by Ramke et al.,[23] which found a quarter of Māori and half of Pacific people did not attend for diabetic retinal screening. Prevalence of diabetes has been shown to be higher in Māori and Pacific peoples compared with NZ Europeans,[24] and Pacific peoples have been shown to have a higher prevalence of severe retinopathy compared with NZ Europeans.[25] Qualitative research on understanding of diabetes among Pacific peoples with end-stage renal disease by Schmidt-Busby et al.[26] has demonstrated various barriers to care. Schmidt-Busby et al. described how understanding of diabetes is often shaped by intergenerational beliefs about diabetes, and so misunderstanding of diabetes could become entrenched. Participants also described health as not being a central priority in otherwise busy lives, particularly due to the lack of symptoms in the early stages of diabetes. There was also sometimes misunderstanding of information given by healthcare professionals, or a perceived lack of communication of the complications of diabetes from health professionals. Another study by Simmons et al. on personal barriers to diabetes care among different ethnic groups in South Auckland revealed that the personal cost of accessing care was a more significant barrier for Māori and Pacific peoples than for NZ Europeans.[22] In addition, Māori were significantly more likely than NZ Europeans to prefer using alternative health models. A qualitative study on barriers to retinal screening in patients at a large rural general practice in Te Tai Tokerau also showed that Māori experienced a greater number of barriers to screening compared with NZ Europeans, which included work, financial barriers (particularly in relation to petrol costs), other health issues limiting mobility, and family priorities, in addition to higher levels of distrust in the health system.[27]

In accordance with previous studies from overseas,[11–14,19] this study found socio-economic deprivation to be associated with non-attendance at diabetic retinal screening. A large multicentre study of patients (n=79,775) with diabetic retinopathy referred to secondary care in the UK demonstrated that socio-economic deprivation was associated with late presentation of diabetic eye disease and a higher risk of significant vision loss at the time of presentation.[28] Despite the presence of 23 hospital- and community-based clinics in areas experiencing high levels of socio-economic deprivation, inequity in access to retinal screening is still present in the Te Tai Tokerau Region. This may be due to financial or geographical barriers affecting access. A study of non-attendance at diabetic retinal screening in Dundee, Scotland by Leese et al.[11] found that distance to screening did not increase the risk of non-attendance, although the average travel distance to clinic was small at 3.3 miles. Another study in Ireland did demonstrate lower uptake of retinal screening in participants who had to travel over 60 kilometres to a screening centre.[29] A geographical information systems (GIS) study may be useful to identify whether geographical barriers affect access to screening.

A qualitative study on patients' attitudes and experiences of diabetic retinal screening in the UK highlighted several barriers to screening, including lack of understanding of the consequences of diabetic retinopathy, lack of understanding about the difference between retinal screening and routine optometry visits, constraints due to work commitments, inconvenience due to multiple clinic attendances in various diabetic clinics and transport issues (particularly if mydriatic drops were used).[30] Similar barriers were observed in a study on diabetic retinal screening attendance in Te Tai Tokerau; however, all may not be applicable due to the distinct geographical and cultural differences between the two populations.[27] Transport issues and inconvenience may be of particular pertinence in Te Tai Tokerau due to the highly rural population, with limited access to public transport, and with a large proportion of the population experiencing high levels of socio-economic deprivation. Assistance with transport costs or the provision of transport to screening appointments could be considered as a method of increasing access. In addition, the use of smartphone-based screening devices could allow retinal screening to occur in general practices, thus allowing patients to have screening performed at locations closer to home and in conjunction with their other diabetes care. Collaboration with local iwi and community groups could be considered to raise awareness about the importance of diabetic retinal screening. In addition, clinician education around Māori models of healthcare may strengthen clinician–patient relationships, and thus may help improve trust in the health system.

This study has several limitations. Firstly, other possible confounding factors such as duration of diabetes and distance to screening unit were not studied due to lack of data availability. Secondly, given the unique demographic profile of Te Tai Tokerau, the results of this study may not be generalisable to the entire Aotearoa New Zealand population. Strengths of this study include the availability of data for a large cohort. In addition, to our knowledge this is the first study in Aotearoa New Zealand to examine the effects of socio-economic deprivation on access to diabetic retinal screening.

This study highlights the need for increased active engagement of younger persons, people from areas of high socio-economic deprivation and Māori and Pacific peoples, with diabetic retinal screening. Qualitative studies have shown that these groups experience significant barriers to screening. Strategies to improve access to retinal screening to prevent the risk of sight-threatening diabetic eye disease should be explored and implemented.

COMPETING INTERESTS
Nil.

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REFERENCES

1. Leasher JL, Bourne RR, Flaxman SR, et al. Global Estimates on the Number of People Blind or Visually Impaired by Diabetic Retinopathy: A Meta-analysis From 1990 to 2010. Diabetes Care. 2016 Sep;39(9):1643-9. doi: 10.2337/dc15-2171.
2. Liew G, Michaelides M, Bunce C. A comparison of the causes of blindness certifications in England and Wales in working age adults (16-64 years), 1999-2000 with 2009-2010. BMJ Open. 2014 Feb;4(2):e004015. doi: 10.1136/bmjopen-2013-004015.
3. Kashim RM, Newton P, Ojo O. Diabetic Retinopathy Screening: A Systematic Review on Patients' Non-Attendance. Int J Environ Res Public Health. 2018 Jan 19;15(1):157. doi: 10.3390/ijerph15010157.
4. Te Whatu Ora – Health New Zealand. Virtual Diabetes Register and web tool [Internet]. Wellington: Te Kāwanatanga o Aotearoa New Zealand Government; 2023 Jun [cited 2021 May 7]. Available from: http://www.health.govt.nz/our-work/diseases-and-conditions/diabetes/aboutdiabetes/virtualdiabetes-register-vdr.
5. Atkinson J, Crampton P, Salmond C. NZDep2018 analysis of census 2018 variables [Internet]. Otago: University of Otago; 2021 [cited 17 Oct 2022]. Available from: https://www.otago.ac.nz/wellington/departments/publichealth/otago831000.pdf.
6. Kukkady S, Kool B, Emma S, et al. The prevalence of diabetes mellitus and retinopathy among Pacific peoples residing in South Auckland, New Zealand. Integrative Obes Diabetes. 2017;3(1):1-6. doi: 10.15761/IOD.1000167.
7. Papali'i-Curtin AT, Dalziel DM. Prevalence of diabetic retinopathy and maculopathy in Northland, New Zealand: 2011-2012. N Z Med J. 2013 Sep 27;126(1383):20-8.
8. Chang LY, Lee AC, Sue W. Prevalence of diabetic retinopathy at first presentation to the retinal screening service in the greater Wellington region of New Zealand 2006-2015, and implications for models of retinal screening. N Z Med J. 2017 Feb 17;130(1450):78-88.
9. Lawrenson R, Gibbons V, Joshy G, Choi P. Are there disparities in care in people with diabetes? A review of care provided in general practice. J Prim Health Care. 2009 Sep;1(3):177-83.
10. Moreton RBR, Stratton IM, Chave SJ, et al. Factors determining uptake of diabetic retinopathy screening in Oxfordshire. Diabet Med. 2017 Jul;34(7):993-999. doi:10.1111/dme.13350.
11. Leese GP, Boyle P, Feng Z, et al. Screening uptake in a well-established diabetic retinopathy screening program: the role of geographical access and deprivation. Diabetes Care. 2008 Nov;31(11):2131-5. doi:10.2337/dc08-1098.
12. Lawrenson JG, Bourmpaki E, Bunce C, et al; EROS Study Group. Trends in diabetic retinopathy screening attendance and associations with vision impairment attributable to diabetes in a large nationwide cohort. Diabet Med. 2021 Apr;38(4):e14425. doi: 10.1111/dme.14425.
13. Gulliford MC, Dodhia H, Chamley M, et al. Socio-economic and ethnic inequalities in diabetes retinal screening. Diabet Med. 2010 Mar;27(3):282-288. doi: 10.1111/j.1464-5491.2010.02946.x.
14. Millett C, Dodhia H. Diabetes retinopathy screening: audit of equity in participation and selected outcomes in South East London. J Med Screen. 2006;13(3):152-5. doi: 10.1258/096914106778440608.
15. Manatū Hauora – Ministry of Health. Diabetic Retinal Screening, Grading, Monitoring and Referral Guidance [Internet]. Wellington: Manatū Hauora – Ministry of Health; 2016 [cited 17 Jun 2021]. Available from: https://www.health.govt.nz/system/files/documents/publications/diabetic-retinal-screening-grading-monitoring-referral-guidance-mar16.pdf.
16. Manatū Hauora – Ministry of Health. HISO 10001:2017 Ethnicity Data Protocols [Internet]. Wellington: Manatū Hauora – Ministry of Health; 2017 Sep [cited 17 Jun 2021]. Available from: https://www.moh.govt.nz.
17. Salmond C, Crampton P, Sutton F, Atkinson J.

NZDep2013 Index of Deprivation [Internet]. Wellington: University of Otago, Wellington; 2014 [cited 11 Dec 2022]. Available from: https://www.otago.ac.nz/wellington/departments/publichealth/research/hirp/otago020194.html.

18. Reda E, Dunn P, Straker C, et al. Screening for diabetic retinopathy using the mobile retinal camera: the Waikato experience. N Z Med J. 2003 Aug 22;116(1180):U562.
19. An J, Niu F, Turpcu A, et al. Adherence to the American Diabetes Association retinal screening guidelines for population with diabetes in the United States. Ophthalmic Epidemiol. 2018 Jun;25(3):257-265. doi: 10.1080/09286586.2018.1424344.
20. Scanlon PH, Stratton IM, Leese GP, et al. Screening attendance, age group and diabetic retinopathy level at first screen. Diabet Med. 2016 Jul;33(7):904-11. doi: 10.1111/dme.12957.
21. Lake AJ, Browne JL, Rees G, Speight J. What factors influence uptake of retinal screening among young adults with type 2 diabetes? A qualitative study informed by the theoretical domains framework. J Diabetes Complications. 2017 Jun;31(6):997-1006. doi: 10.1016/j.jdiacomp.2017.02.020.
22. Simmons D, Weblemoe T, Voyle J, et al. Personal barriers to diabetes care: lessons from a multi-ethnic community in New Zealand. Diabet Med. 1998 Nov;15(11):958-64. doi: 10.1002/(SICI)1096-9136(1998110)15:11<958::AID-DIA687>3.0.CO;2-9.
23. Ramke J, Jordan V, Vincent AL, et al. Diabetic eye disease and screening attendance by ethnicity in New Zealand: A systematic review. Clin Exp Ophthalmol. 2019 Sep;47(7):937-947. doi: 10.1111/ceo.13528.
24. Joshy G, Simmons D. Epidemiology of diabetes in New Zealand: revisit to a changing landscape. N Z Med J. 2006 Jun;119(1235):U1999.
25. Simmons D, Clover G, Hope C. Ethnic differences in diabetic retinopathy. Diabet Med. 2007 Sep;24(10):1093-8. doi: 10.1111/j.1464-5491.2007.02227.x.
26. Schmidt-Busby J, Wiles J, Exeter D, Kenealy T. Understandings of disease among Pacific peoples with diabetes and end-stage renal disease in New Zealand. Health Expect. 2019 Oct;22(5):1122-1131. doi: 10.1111/hex.12946.
27. Harbers A, Davidson S, Eggleton K. Understanding barriers to diabetes eye screening in a large rural general practice: an audit of patients not reached by screening services. J Prim Health Care. 2022 Sep;14(3):273-279. doi: 10.1071/HC22062.
28. Denniston AK, Lee AY, Lee CS, et al. United Kingdom Diabetic Retinopathy Electronic Medical Record (UK DR EMR) Users Group: report 4, real-world data on the impact of deprivation on the presentation of diabetic eye disease at hospital services. Br J Ophthalmol. 2019 Jun;103(6):837-843. doi: 10.1136/bjophthalmol-2018-312568.
29. Greenan E, Salim M, Coakley DN, James M. The effect of geodemographic factors on the attendance rates at a regional diabetic retinopathy treatment centre. Ir J Med Sci. 2019 Nov;188(4):1207-1212. doi: 10.1007/s11845-019-02009-4.
30. Hipwell AE, Sturt J, Lindenmeyer A, et al. Attitudes, access and anguish: a qualitative interview study of staff and patients' experiences of diabetic retinopathy screening. BMJ Open. 2014 Dec 15;4(12):e005498. doi: 10.1136/bmjopen-2014-005498.

Exploring the impact of e-learning modules and webinars on health professionals’ understanding of the End of Life Choice Act 2019: a secondary analysis of Manatū Hauora – Ministry of Health workforce survey

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ABSTRACT

AIM: To explore the importance of health workforce training, particularly in newly regulated healthcare practices such as assisted dying (AD). This study aims to analyse the socio-demographic factors associated with health professionals’ completion of the e-learning module and attendance at the two webinars provided by the New Zealand Ministry of Health – Manatū Hauora (MH) and whether completion of the e-learning module and webinars supported health professionals’ understanding of the *End of Life Choices Act 2019*.

METHOD: Secondary analysis of the MH workforce surveys conducted in July 2021.

RESULTS: The study findings indicate that health professionals who are older, of Pākehā/European ethnicity and work in hospice settings are more likely to complete the e-learning module, while females are more likely to attend webinars.

CONCLUSION: Despite low completion and attendance rates, the study highlights the positive association between training and health professionals’ overall understanding of the *Act*. These results emphasise the need for enhancing training programmes to increase health professionals’ knowledge and competence with AD. Furthermore, the research proposes focussing on healthcare practitioners in the early stages of their careers and not directly engaged in offering AD services, as well as Māori and Pasifika health practitioners.

Health workforce training has been regarded as essential to maintain high-quality standards of care and to ensure the safety of providers and recipients of care. Training in newly regulated healthcare, such as assisted dying (AD), can support translating the legislation into practice. Crucially, appropriate AD training clarifies the roles and responsibilities of health professionals in caring for individuals with life-limiting illnesses. AD training has been considered a safeguard for standardising baseline knowledge, enhancing the quality and consistency of decision making by health professionals and supporting the safe and effective operation of the AD process.[1]

In jurisdictions that allow the practice, AD training is provided through online modules, courses, elective programmes and practice guidelines on relevant topics, including palliative care, AD law and regulations, communication skills and end-of-life decision making.[2–5] Despite a proven need for AD training programmes and more formalised and standardised education and training, most jurisdictions have no mandatory training within their statutory practice guidelines.[1,4,6–10] While research from Belgium, the Netherlands, Australia and Canada shows the benefit of training in improving practitioners’ competency in applying the law and the quality of AD consultation,[2,3,9,11,12] determining how best to educate health professionals and students remains a challenge.

In Aotearoa New Zealand, AD was introduced under the *End of Life Choice* (EOLC) *Act 2019* (the *Act*) and is part of the mainstream publicly funded healthcare, with the Manatū Hauora – Ministry of Health (MH) responsible for implementing AD services. During the first 12 months of implementation, MH launched an initial e-learning module intending to support health professionals develop a working knowledge of their roles and responsibilities under the *Act*, including the right to conscientiously object. This 20-minute e-learning module covers 1) an overview of the *Act* and AD, 2) key safeguards in the AD process, and 3) how AD fits into existing health "professionals" roles and responsibilities. Complementing the e-learning module, MH hosted a series of five webinars: Learning from international experience (June 2021), Patient perspective on assisted dying (July 2021), Whānau/family centred end of life care (August 2021), The role of the wider workforce (September 2021), and A person's right and a practitioner's responsibilities (October 2021).[13,14]

In July 2021, MH undertook a national health workforce survey to collect information on training, support and planning related to the provision of AD. This study aims to identify i) the socio-demographic factors associated with health professionals' completion of the e-learning module and attendance at the first two webinars, and ii) the extent to which these activities supported understanding of the *Act* using data from the national survey.

Method

Research design and participants

We conducted a secondary analysis of the EOLC *Act* workforce online survey. This cross-sectional survey was designed and administered by MH in July 2021. Ethics approval was granted by The University of Auckland Human Participants Ethics Committee (Reference Number UAHPEC24110).

Health professionals from a wide range of disciplines participated in the survey. MH employed "snowball" sampling to distribute the survey to various health and professional organisations during the first three weeks of July 2021. Each organisation invited members or employees to participate and disseminate the survey to other relevant networks. Among the organisations invited to respond were district health boards (DHBs), hospices, professional organisations such as medical colleges, the Pharmaceutical Society of New Zealand, the New Zealand Nurses Organisation as well as education providers (e.g., medical schools), allied organisations (e.g., Cancer Control Agency), government agencies (e.g., Department of Corrections, the Ministry of Māori Development, Disability Support Services, Health Quality & Safety Commission, and the Health and Disability Commissioner), Māori health services and associated organisations, disability organisations and advocates for aged care.

Workforce surveys

MH developed 16 questions to collect information about the following topics: 1) socio-demographic information: age, gender, ethnicity, health profession, work setting, and location, 2) overall understanding and understanding of eligibility criteria and health professionals' specific obligations, 3) training, support and planning needs, and 4) areas of interest going forward, including the implementation of AD. Only the questions most pertinent to the current study were included in the analysis (see Table 1). Completion of the survey took approximately 10 minutes.

Data cleaning and analysis

The Statistical Package for Social Sciences (SPSS) software, Version 28.0 (IBM), was used to perform the analyses. Before the analyses, the data were checked for missing values, and any necessary data cleaning was performed. Responses falling under the "would rather not say" category or not answered were classified as missing data and excluded from further analyses. We described the distribution of socio-demographic variables among survey respondents who i) did or did not complete the e-learning module and ii) attended or did not attend the webinar(s).

Using Spearman's rank correlation, we analysed the relationship between three variables related to the "understanding of the *Act*" section. The test indicated a strong positive correlation ($p \leq 0.01$) between health professionals' overall understanding of the *Act* and understanding of eligibility criteria and obligations and the right to object conscientiously. Based on the strength of the correlation, we focussed on "overall understanding" in subsequent analyses. We reported the distribution of the Likert scale responses to the "overall understanding of the *Act*" according to whether respondents completed the e-learning module and attended the webinar(s).

A logistic regression analysis was then performed to determine i) the socio-demographic factors associated with e-learning module completion and webinar attendance, ii) whether completing the e-learning module or attending the webinars (unadjusted and adjusted for age, gender, ethnicity and work setting) affected the overall understanding of the *Act*.

Due to the small number of responses, some categories were combined in the logistic regression, as detailed in the footnotes for Table 4. For example, the option of Māori versus non-Māori was not feasible for logistic regression due to the limited number of Māori participants. Therefore, the ethnicities of Māori, Pasifika, Asian and Other were combined into one category called "Non-European." A 95% confidence interval was used for the odds ratios and 5% ($p<0.05$) for statistical significance.

Results

The calculation of the response rate was hindered by the lack of information from MH regarding the total number of health professionals/organisations approached for survey participation. However, a total of 859 responses were available for analysis. Most respondents were aged 45 years and over (63.9%), were female (70%), identified as Pākehā/European (81%) and worked as medical practitioners (51.5%). Respondents came from all 20 DHBs, with the highest proportion from Auckland Central (23.2%). Table 2 presents respondents' socio-demographic details on age, gender, ethnicity, work location, professional background and work settings.

Completion of the e-learning module

The e-learning module was completed by 200 (23.2%) survey respondents, who were most frequently aged 55–65 (37.4%), were female (75.6%), identified as Pākehā/European (91.3%), were located in the North Island (74.5%) and worked as medical practitioners (49.5%) and in hospitals (46.5%). Two Māori (1.0%) and two Pasifika (1.0%) health professionals completed the e-learning, whereas 10 Asian health professionals (5.1%) did so (Table 2). Among health professionals who completed the e-learning module, the majority (91.5%) reported having a "good" or "very good" overall understanding of the *Act*. In contrast, of health professionals who did not complete the e-learning module, only 52.5% reported having a "good" or "very good" overall understanding of the *Act* (Table 3).

Attendance at webinars

One hundred and fifty-two (17.6%) survey respondents attended one or both webinars. The largest group of these health professionals by each category were female (81.3%), aged 55–66 (34%), identified as Pākehā/European (83.7%), were located in the North Island (69.1%) and worked as medical practitioners (48%) and in hospitals (39.9%). Five Māori (3.4%), one Pasifika (0.7%) and 53 Asian (7.8) health professionals attended the webinar(s). Among health professionals who attended the webinar(s), the majority (81.6%) reported having a "good" or "very good" overall understanding of the *Act*. In comparison, for health professionals who did not attend the webinars, only 57.2% reported having a "good" or "very good" overall understanding of the *Act* (Table 3).

Table 4 presents the logistic regression results on the socio-demographic factors associated with e-learning module completion and webinar attendance. Health professionals aged 45–55 (OR=2.12, CI=1.19–3.79) and those over 55 (OR=2.42, CI=1.38–4.25) had a higher likelihood of completing the module than those under 35 years. Regarding ethnicity, individuals identifying as non-European were less than half as likely (OR=0.43, CI=0.24–0.75) to complete the e-learning module compared to Pākehā/European health professionals. Those working in a hospice setting (OR=2.44, CI=1.31–4.54) were more than twice as likely to complete the e-learning module than those working in general practice. Gender was the only significant factor associated with webinar attendance, with females being almost twice as likely to attend or watch the webinars (OR=1.96, CI=1.21–3.19).

We acknowledge the over-representation of Pākehā/Europeans in completing the e-learning module and webinars. We included the ethnicity variable in our regression model, along with other socio-demographic factors (age, gender, DHB, health profession, and work setting), and Pākehā/European ethnicity remained to be a significant factor associated with e-learning completion but not with webinar completion (Table 4).

Table 5 presents the logistic regression results with the overall understanding of the *Act* as the dependent variable. Both training methods showed increased odds of understanding the *Act*, with e-learning module completion having a stronger association. Health professionals who had completed the e-learning module were over eight times more likely to have a "good" or "very good" understanding of the *Act* compared with those who had not (OR=8.31, CI=4.90–14.09). In contrast, the overall understanding of the *Act* is two times higher in those who attended or watched at least one webinar than those who did not (OR=1.99, CI=1.24–3.19).

Areas of interest for future updates

As indicated in Table 6, respondents expressed interest in receiving updates on the implementation of the *Act*, particularly concerning their obligations as health professionals (73.1%), information about support for patients and whānau (families) (57%) and conscientious objection rights (53.6%).

Table 1: Key questions of relevance to this study in the July 2021 workforce survey.

Sections	Response options	Dichotomous categories*
	Likert scale	
Understanding of the Act 1. How well do you think you understand the *End of Life Choice Act* overall? 2. How well do you think you understand the eligibility criteria and circumstances where the process must end, as outlined in the *Act*? 3. How well do you think you understand specific obligations on health practitioners as outlined in the *Act*, including the right of conscientious objections?	a. Not at all b. I have a limited understanding c. I have a good understanding, but there are some gaps d. I have a very good understanding	a & b c &d
Workforce training, support and planning 1. Have you completed the first online learning module focussed on the *Act* and the introduction of AD in NZ? • If yes, how well did the module support your understanding of the *Act*? 2. Have you attended or watched a recording of any of the online webinars that have been produced on the implementation of AD? • If yes, how useful did you find the webinar(s) in supporting your understanding of the topics covered?	a. Not at all b. To a limited degree c. It was helpful, but I still have some gaps d. Provided me with a very good understanding e. Not applicable	
Going forward	**Multiple choices**	
1. What areas are you most interested in, in relation to the implementation of AD in New Zealand? Select all that apply.	a. Education and training b. How AD services will be provided by my employer c. How statutory committees and roles will work d. My rights regarding conscientious objection e. Support for patients and whanau f. The obligations on me as a health professional g. What the funding arrangements are for AD h. Other	

[*] Dichotomous in statistics refers to the division of variables into two groups/values to conduct a logistic regression to determine the reason-result relationship of the independent variable(s) with the dependent variable.

Table 2: Characteristics of respondents who did or did not complete the e-learning module and who did or did not attend the webinars in June and/or July 2021.

Socio-demographic details		**Total (N=859)** n (%)	**E-learning module completion**		**Webinar attendance**	
			Yes **N=200** **n (%)**	**No** **N=659** **n (%)**	**Yes** **N=152** **n (%)**	**No** **N=707** **n (%)**
Age[a]	Under 35	146 (17.0)	20 (10.1)	126 (19.2)	23 (15.3)	123 (17.5)
	35–45	159 (18.5)	31 (15.7)	128 (19.5)	21 (14.0)	138 (19.6)
	45–55	233 (27.1)	60 (25.8)	173 (74.2)	48 (32.0)	185 (26.3)
	55–65	254 (29.6)	74 (37.4)	180 (26.4)	51 (34.0)	203 (28.8)
	Over 65	62 (7.2)	13 (6.6)	49 (7.5)	7 (4.7)	55 (7.8)
Gender[b]	Male	251 (29.2)	48 (24.4)	203 (30.9)	28 (18.7)	223 (31.7)
	Female	601 (70.0)	149 (75.6)	452 (68.9)	122 (81.3)	479 (68.1)
	Gender diverse	1 (0.1)	0 (0.0)	1 (100)	0 (0.0)	1 (0.1)
Ethnicity[c]	Pākehā/European[d]	696 (81.0)	179 (91.3)	517 (81.8)	123 (83.7)	573 (84.1)
	Asian[e]	63 (7.3)	10 (5.1)	53 (8.4)	10 (6.8)	53 (7.8)
	Māori	12 (1.4)	2 (1.0)	10 (1.6)	5 (3.4)	7 (1.0)
	Pasifika	7 (0.8)	2 (1.0)	5 (0.8)	1 (0.7)	6 (0.9)
	Other[f]	50 (5.7)	3 (1.5)	47 (7.4)	8 (5.4)	42 (6.2)
District health board[g]	North Island	632 (73.6)	149 (74.5)	483 (73.3)	105 (69.1)	527 (74.5)
	South Island	227 (26.4)	51 (25.5)	176 (26.7)	47 (30.9)	180 (25.5)
Health profession	Medical practitioner	442 (51.5)	99 (49.5)	343 (52.0)	73 (48.0)	369 (52.2)
	Medical practitioner (psychiatrist)[h]	26 (3.0)	10 (5.0)	16 (2.4)	3 (2.0)	23 (3.3)
	Nurse practitioner	40 (4.7)	15 (7.5)	25 (3.8)	10 (6.6)	30 (4.2)
	Nurse	186 (21.7)	39 (19.5)	147 (22.3)	39 (25.7)	147 (20.8)
	Pharmacist	63 (7.3)	9 (4.5)	54 (8.2)	9 (15.9)	54 (7.6)
	Other[i]	102 (11.9)	28(27.5)	74 (11.2)	18 (11.8)	84 (11.9)

Table 2 (continued): Characteristics of respondents who did or did not complete the e-learning module and who did or did not attend the webinars in June and/or July 2021.

Work setting	Aged residential care	55 (6.4)	12 (6.0)	43 (6.5)	16 (10.5)	39 (5.5)
	Community	32 (3.7)	10 (5.0)	22 (3.3)	4 (2.6)	28 (4.0)
	General practice	202 (23.5)	40 (20.0)	162 (24.6)	33 (21.7)	169 (23.9)
	Hospital	409 (47.6)	93 (46.5)	316 (48.0)	60 (39.5)	349 (49.4)
	Hospice	78 (9.1)	29 (14.5)	49 (7.4)	22 (14.5)	56 (7.9)
	Pharmacy	32 (3.7)	4 (2.0)	28 (4.2)	5 (3.3)	27 (3.8)
	Specialist practice	9 (1.0)	3 (1.5)	6 (0.9)	0 (0.0)	9 (1.3)
	Other[j]	42 (4.9)	9 (4.5)	33 (5.0)	12 (7.9)	30 (4.2)

[a] Age groups listed in the surveys overlapped: 35–45, 45–55 and 55–65, where they should have been discrete: 35–44, 45–54 and 55–64. Missing data in age category n=5.

[b] Missing data in gender category n=6.

[c] Missing data in ethnicity category n=31.

[d] Pākehā refers to white/European New Zealanders. European refers to other Europeans.

[e] Asian in this study refers to Chinese, Indian, Filipino, Sri Lankan, Malaysian, South East Asian, etc.

[f] MELAA (Middle Eastern/Latin American/African) ethnicities were grouped under the "Other" category due to the small number of responses.

[g] North Island DHBs were combined under the new category of "North Island", and South Island DHBs were combined under the new category of "South Island" for data analysis due to the small number in each DHB.

[h] MH had presented "psychiatrist" as a distinct category.

[i] Other health professionals included clinical academics, allied health, clinical managers, mental/social health workers and midwives.

[j] Other work settings included educational institutions, urgent care, prison/corrections, non-government organisations and government agencies.

Table 3: Overall understanding of the *Act* rated by i) respondents (n=855) who completed versus those who did not complete the e-learning module; and ii) respondents (n=856) who attended the webinar(s) versus those who did not attend the webinar(s).

		Not at all **N=26** **n (%)**	**Limited** **N=304** **n (%)**	**Good** **N=384** **n (%)**	**Very good** **N=145** **n (%)**
E-learning module completion	Yes	0 (0.0)	17 (8.5)	112 (56.0)	71 (35.5)
	No	26 (3.9)	287 (43.6)	272 (41.3)	74 (11.2)
Webinar attendance	Yes	0 (0.0)	28 (18.4)	79 (52.0)	45 (29.6)
	No	26 (3.7)	276 (39.0)	305 (43.1)	100 (14.1)

Table 4: Logistic regression of e-learning module completion and webinar attendance (June and/or July 2021).

Socio-demographic details		**E-learning module completion**		**Webinar attendance**	
		OR[a] (CI[b] 95%)	***P*-value**	**OR[a] (CI[b] 95%)**	***P*-value**
Age	Under 35[c]	REF	0.013*	REF	0.154
	35–45	1.58 (0.84–2.98)		0.71 (0.36–140)	
	45–55	2.12 (1.19–3.79)		1.39 (0.78–2.46)	
	Over 55[d]	2.42 (1.38–4.25)		1.19 (0.68–2.09)	
Gender[e]	Female (versus male)	1.47 (0.98–2.21)	0.061	1.96 (1.21–3.19)	0.006*
Ethnicity[f]	Non-European (versus Pākehā/European[g])	0.43 (0.24–0.75)	0.004*	1.09 (0.65–1.87)	0.732
District health board[h]	South Island (versus North Island)	0.92 (0.63–1.35)	0.697	1.24 (0.83–1.87)	0.287
Health profession[i]	Medical practitioner	REF	0.332	REF	0.442
	Nurse/nurse practitioner	0.72 (0.46–1.13)		0.88 (0.55–1.41)	
	Other	0.78 (0.48–1.27)		0.69 (0.40–1.21)	
Work setting[j]	General practice	REF	0.039*	REF	0.064
	Hospital	1.36 (0.88–2.12)		1.06 (0.64–1.74)	
	Hospice	2.44 (1.31–4.54)		2.18 (1.12–4.23)	
	Other	1.27 (0.72–2.23)		1.56 (0.86–2.85)	

[*] <0.05
[**] <0.01
[a] OR = Odds ratio
[b] CI = Confidence interval
[c] The two categories of “under 25” and “25–35” merged into one category of “under 35” for data analysis due to the small number of responses.
[d] The two categories of “55–65” and “over 65” merged into one category of “over 55” for data analysis due to the small number of responses.
[e] The “gender diverse” category was excluded from the analysis due to the small number of responses.
[f] The four categories of Asian, Māori, Pasifika and Other combined under the new category of “non-European” due to the small number of responses.
[g] Pākehā refers to white/European New Zealanders. European refers to other Europeans.
[h] North Island DHBs were combined under the new “North Island” and South Island DHBs under the “South Island” categories.
[i] “Psychiatrist” was combined under “Medical practitioners”. “Nurse” and “nurse practitioners” were merged. “Pharmacist” was combined under “Other”.
[j] “Aged residential care”, “Community” and “Pharmacy” were combined under “Other”.

Table 5: Logistic regression: binary outcome = overall understanding of the *Act* as "not at all or limited" versus "good or very good". Independent variables = e-learning module completion + webinar attendance.

Variable		**Logistic regression model**			
		Unadjusted OR[a] (CI[b] 95%)	***P*-value**	**Adjusted OR[a] (CI[b] 95%)**	***P*-value**
Module completion	Yes (versus no)	8.31 (4.90–14.09)	0.001**	8.17 (4.72–14.2)	0.001**
Webinar(s) attendance	Yes (versus no)	1.99 (1.24–3.19)	0.004*	2.10 (1.27–3.47)	0.003*

*<0.05
**<0.01
[a] OR = Odds ratio
[b] CI = Confidence interval

Table 6: Respondents' areas of interest for future updates concerning the implementation of the *Act*.

	Sum **N (%)**
The obligations on me as a health professional	628 (73.1)
Support for patients and whānau (families)	490 (57.0)
My rights regarding conscientious objection	460 (53.6)
Education and training	454 (52.9)
How assisted dying services will be provided by my employer	407 (47.4)
How the statutory committees and roles will work	301 (35.0)
What the funding arrangements are for assisted dying	294 (34.2)
Other	63 (7.3)

Discussion

In the year preceding the implementation of AD in New Zealand, health professionals were provided with specific AD training through an e-learning module and a series of webinars. This study marks the first national large-scale data gathered in New Zealand on socio-demographic factors associated with health professionals accessing training modules and the relationship of training to perceived knowledge and understanding of the *Act*. The novelty of the data in this study brings about a certain degree of uncertainty in the conclusions reached.

The results reveal a significant association between older age, Pākehā/European ethnicity and working in a hospice setting with e-learning module completion. Additionally, the female gender is associated with higher webinar attendance. The majority of survey respondents did not complete the e-learning (76.7%) or attend/watch the webinars (82.3%). The decision to adopt e-learning is influenced by several factors, including the relevance of module content to health professionals' practice, organisational considerations such as availability of dedicated time and space in workplaces, support of e-learning and personal factors[14] like conscientious objection to AD. In New Zealand, no individual or organisation is compelled to provide AD, and all hospices, except one, have chosen not to do so, practising their right to object to AD.[15] When personal factors may influence the need to learn about AD, organisation factors may impact the practical considerations to either facilitate or limit the update of e-learning. Another plausible explanation could be that the *Act* had only been recently legalised (by 6 months) at the time of the survey, with only one e-learning module and two webinars available to health professionals. Since then, MH has launched three more e-learning modules for all health professionals focussing on professionals' rights and responsibilities, the process of accessing AD (including the roles of different health practitioners) and how to respond appropriately when an AD request is raised.[16] Following the initial module, MH also launched five e-learning modules for medical practitioners providing the AD service (practitioners are required to complete these modules to claim funding for providing AD services), which address 1) application and initial opinion about eligibility, 2) independent assessment of eligibility, 3) assessment of competency, 4) deciding about eligibility, and 5) prescribing and administering medication.[16,17] The series of five webinars covered a range of topics related to AD and the implementation of the *Act*, with the first two (included in this study) including international experience and patient perspectives.

Interestingly, despite the low completion and attendance rates and the less generic content of training resources available after the survey, our results indicate a positive relationship between training and understanding the *Act*. This result indicates the importance of training in providing health professionals with a means to increase their knowledge and competence with AD, reflecting findings reported overseas. In Belgium and the Netherlands, specifically trained physicians who provide secondary consultation during eligibility assessment were found to be more skilful and critical, contributing to a higher-quality consultation.[9,11] On a different level, the impact of training has also been positive in helping Canadian medical students to become more comfortable discussing AD and to display more positive self-rated attitudes toward AD,[12] which may, ultimately, increase workforce availability and integration of quality end-of-life care for those patients requesting an assisted death.

Survey participants expressed a desire for additional education and training (52.9%), particularly regarding health professionals' obligations (73.1%), support for patients and whānau (57%) and conscientious objection rights (53.6%). Similarly, studies on the opinions of geriatricians in Australia and New Zealand and medical oncology groups in Australia have highlighted the desire of physicians for more training and clarity on AD, such as the boundaries of eligibility requirements, performing capacity assessment and counselling patients requesting AD.[18,19]

Identifying and addressing educational gaps and challenges in delivering education among health professionals is crucial as this is likely to impact the future availability of AD.[20] Inadequate education can leave doctors and health practitioners feeling unprepared and incompetent to manage AD conversations with patients, resulting in patients receiving misinformation about AD pathways, procedures and eligibility processes.[1] Canadian research on nursing and pharmacy students' experiences with AD identified concerns regarding saying the "wrong" things when speaking with patients and families, not knowing the AD process, dispensing ineffective AD medication, being unable to manage unexpected side effects and emotional impact, and resolving moral and personal conflicts.[12,21,22]

Our results show a higher rate of e-learning module completion among health professionals over 45 years of age compared to those under 35. This result suggests a necessity to target health professionals in their early career years who are less directly involved in providing AD services. As Brown et al. claim, teaching end-of-life concepts focussing on patient- and family-centred care, such as AD, can enable students to reflect on their conscience and ethical considerations. Additionally, it can help them comprehend the legal frameworks, practice guidelines and competencies related to providing quality care.[8]

Additionally, Māori and Pasifika health professionals are other groups that could benefit from additional training in New Zealand. According to the MH report, of the 814 patients who applied for AD between 7 November 2021 and 31 December 2022, 44 (5.4%) were Māori and 3 (0.3%) were Pasifika, indicating an interest in AD among Māori.[23] However, our results indicate a relatively low uptake of the e-learning module and webinar(s) attendance among Māori and Pasifika health professionals. More data need to be gathered to clarify whether this rate is proportionate to the numbers of Māori and Pasifika health professionals in the New Zealand healthcare workforce. To optimise access and quality care for Māori, developing and providing appropriate training for health professionals caring for Māori at the end of their life seems necessary. Under Te Tiriti o Waitangi, the government is legally obligated to ensure equitable health outcomes for Māori.[24] This obligation is also conveyed to health researchers to ensure that research supports Māori development, including workforce development, and incorporates traditional or contemporary Māori processes.[24] This calls for further attempts to develop training that may, for example, include improved knowledge about tikanga around the dying process and cultural support and guidance for patients requesting AD and their whānau. The inclusion of Māori and Pasifika representation in the development of these materials could be enhanced by the use of alternative research approaches. These methods could overcome the observed limited participation of non-European ethnic groups in healthcare surveys, as shown by the findings of this study.

Considering the positive impact of education and training, it would be advantageous to explore various approaches to integrate AD education into existing curricula. In addition, there is a need to identify the best ways to provide AD training programmes to the current health workforce and to evaluate their efficacy through pre- and post-measurements once such training programmes are developed. Attempts to develop learning objectives, educational tools, medical student scope of practice and delivery structure to inform assisted dying curriculum have already begun in Canada.[8,10,25] At the same time, the impact of a mandatory AD program in Australia is currently being evaluated with a view to improvement.[2]

Limitations

MH designed and distributed the survey and collected data without input from the research team, imposing some limitations on the secondary data analysis. Firstly, the survey was distributed in early July 2021, allowing a 3-week window for completion, which resulted in some responses being received prior to the mid-July webinar. Furthermore, no information was collected regarding whether respondents attended one or both webinars held in June and July 2021. Secondly, it remains unclear whether the Ministry considered the content validity of the survey and, if they did, the specific measures taken to ensure its implementation. A third limitation concerns the representativeness of the results, as MH did not provide a comprehensive list of the organisations that received the survey, and the snowball sampling approach precludes the calculation of response rates. Additionally, due to the low uptake of training among non-European health professionals, the ethnic groups, such as Māori and Pasifika, were combined for data analysis. We considered having two options: European versus non-European OR Māori versus non-Māori. Given the small number of Māori participants, the second option was not feasible for logistic regression. This limitation of low uptake prevented us from exploring specific cultural needs and how much this may contribute to ethnic inequality in health.[26] Lastly, the measures of respondent understanding may introduce a potential source of bias. Self-assessment is inherently subjective and context dependent,[27] and reported knowledge may differ from objective measures.[28]

Conclusion

This study offers preliminary insights into the socio-demographic factors linked to the interest of New Zealand health professionals in training related to the *End of Life Choice Act 2019* and AD. The results show that older age, Pākehā/European ethnicity, and working in a hospice setting are significantly associated with completing the e-learning module. In contrast, the female gender is associated with webinar attendance. These results highlight the positive relationship between training and perceived understanding of AD, despite the low completion rate of the initial e-learning module and attendance of one or two webinars. This result emphasises the need to expand training for health professionals and improve their engagement with existing training to increase their knowledge and competence with AD. Future research should prioritise identifying educational gaps and delivery challenges faced by practitioners in training, as well as incorporating traditional or contemporary Māori models of care into AD training, aiming to achieve equitable health outcomes.

COMPETING INTERESTS

AD, RF, MC, XJ, FS, NRH, SB and DM declare no competing interest. GC and JR are members of Support and Consultation for the End of Life in NZ Group. This research is funded by the Auckland Medical Research Foundation.

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REFERENCES

1. White BP, Willmott L, Close E, et al. Development of Voluntary Assisted Dying Training in Victoria, Australia: A Model for Consideration. J Palliat Care. 2021 Jul;36(3):162-7. doi: 10.1177/0825859720946897.
2. Willmott L, Feeney R, Yates P, et al. A cross-sectional study of the first two years of mandatory training for doctors participating in voluntary assisted dying. Palliat Support Care. 2022 Jul 28:1-7. doi: 10.1017/S1478951522000931.
3. Van Wesemael Y, Cohen J, Onwuteaka-Philipsen BD, et al. Establishing specialized health services for professional consultation in euthanasia: experiences in the Netherlands and Belgium. BMC Health Serv Res. 2009 Dec 4;9:220. doi: 10.1186/1472-6963-9-220.
4. MacDonald S, LeBlanc S, Dalgarno N, et al. Exploring family medicine preceptor and resident perceptions of medical assistance in dying and desires for education. Can Fam Physician. 2018 Sep;64(9):e400-e406.
5. Ding JZ, Casey G, Kekewich M, et al. Medical assistance in dying: a structured postgraduate elective to build confidence in caring for patients. Can J Anaesth. 2019 Sep;66(9):1121-1122. doi: 10.1007/s12630-019-01406-8.
6. Frolic A, Swinton M, Oliphant A, et al. Access Isn't Enough: Evaluating the Quality of a Hospital Medical Assistance in Dying Program. HEC Forum. 2022 Dec;34(4):429-455. doi: 10.1007/s10730-022-09486-8.
7. Li M, Watt S, Escaf M, et al. Medical Assistance in Dying - Implementing a Hospital-Based Program in Canada. N Engl J Med. 2017 May 25;376(21):2082-2088. doi: 10.1056/NEJMms1700606.
8. Brown J, Goodridge D, Thorpe L. Medical Assistance in Dying in health sciences curricula: A qualitative exploratory study. Can Med Educ J. 2020 Dec 7;11(6):e79-e89. doi: 10.36834/cmej.69325.
9. Cohen J, Van Wesemael Y, Smets T, et al. Nationwide survey to evaluate the decision-making process in euthanasia requests in Belgium: do specifically trained 2nd physicians improve quality of consultation? BMC Health Serv Res. 2014 Jul 16;14:307. doi: 10.1186/1472-6963-14-307.
10. Oczkowski SJW, Crawshaw D, Austin P, et al. How We Can Improve the Quality of Care for Patients Requesting Medical Assistance in Dying: A Qualitative Study of Health Care Providers. J Pain Symptom Manage. 2021 Mar;61(3):513-521.e8. doi: 10.1016/j.jpainsymman.2020.08.018.
11. Jansen-van der Weide MC, Onwuteaka-Philipsen BD, van der Wal G. Quality of consultation and the project 'Support and Consultation on Euthanasia in the Netherlands' (SCEN). Health

Policy. 2007 Jan;80(1):97-106. doi: 10.1016/j.healthpol.2006.03.005.

12. Bator EX, Philpott B, Costa AP. This moral coil: a cross-sectional survey of Canadian medical student attitudes toward medical assistance in dying. BMC Med Ethics. 2017 Oct 27;18(1):58. doi: 10.1186/s12910-017-0218-5.
13. Nursing Council of New Zealand. End of Life Choice Act Training and Information Sheets [Internet]. 2022 [cited 2023 Feb 17]. Available from: https://www.nursingcouncil.org.nz/NCNZ/News-section/news-item/2021/5/End_of_Life_Act_Training_and_Information_Sheets.aspx#:~:text=The%20first%20online%20training%20module,choose%20not%20to%20be%20involved.
14. Callinan J. Barriers and facilitators to e-learning in palliative care. Int J Palliat Nurs. 2020 Dec 2;26(8):394-402. doi: 10.12968/ijpn.2020.26.8.394.
15. Hospice New Zealand. Assisted dying – our opinion [Internet]. 2023 [cited 2023 Apr 12]. Available from: https://www.hospice.org.nz/euthanasia-our-opinion/.
16. Te Manatū Hauora – Ministry of Health. Assisted dying training resources for health professionals [Internet]. 2023 [cited 2023 Feb 21]. Available from: https://www.health.govt.nz/our-work/life-stages/assisted-dying-service/information-health-professionals/training-resources-health-professionals.
17. Te Manatū Hauora – Ministry of Health. Assisted Dying Service funding and payment [Internet]. 2023 [cited 2023 Feb 21]. Available from: https://www.health.govt.nz/our-work/life-stages/assisted-dying-service/information-health-professionals/assisted-dying-service-provision-and-payment.
18. Munday T, Poon P. Geriatricians' attitudes towards voluntary assisted dying: A survey of Australian and New Zealand Society for Geriatric Medicine members. Australas J Ageing. 2020 Mar;39(1):e40-e48. doi: 10.1111/ajag.12681.
19. Karapetis CS, Stein B, Koczwara B, et al. Medical Oncology Group of Australia position statement and membership survey on voluntary assisted dying. Intern Med J. 2018 Jul;48(7):774-779. doi: 10.1111/imj.13951.
20. Downar J, Francescutti LH. Medical assistance in dying: time for physicians to step up to protect themselves and patients. CMAJ. 2017 Jun 26;189(25):E849-E850. doi: 10.1503/cmaj.170462.
21. Verweel L, Rosenberg-Yunger ZRS, Movahedi T, Malek AH. Medical assistance in dying: Examining Canadian pharmacy perspectives using a mixed-methods approach. Can Pharm J (Ott). 2018 Feb 9;151(2):121-132. doi: 10.1177/1715163518754917.
22. McMechan C, Bruce A, Beuthin R. Canadian Nursing Students' Experiences with Medical Assistance in Dying/Les expériences d'étudiantes en sciences infirmières au regard de l'aide médicale à mourir. Quality Advancement in Nursing Education-Avancées en formation infirmière. 2019;5(1):2. doi: https://doi.org/10.17483/2368-6669.1179
23. Te Manatū Hauora – Ministry of Health. Assisted dying service reporting [Internet]. 2023 [cited 2022 Nov 01 and 2023 Mar 10]. Available from https://www.health.govt.nz/our-work/life-stages/assisted-dying-service/assisted-dying-service-data-and-reporting.
24. Reid P, Paine SJ, Curtis E, et al. Achieving health equity in Aotearoa: strengthening responsiveness to Māori in health research. N Z Med J. 2017 Nov 10;130(1465):96-103.
25. LeBlanc S, MacDonald S, Martin M, et al. Development of learning objectives for a medical assistance in dying curriculum for Family Medicine Residency. BMC Med Educ. 2022 Mar 11;22(1):167. doi: 10.1186/s12909-022-03204-1.
26. Nazroo JY, Karlsen S. Ethnic inequalities in health: social class, racism, and identity. Health Variations Programme. 2001 Sep.
27. Eva KW, Regehr G. Self-assessment in the health professions: a reformulation and research agenda. Acad Med. 2005 Oct;80(10 Suppl):S46-54. doi: 10.1097/00001888-200510001-00015.
28. Austin Z, Gregory PA. Evaluating the accuracy of pharmacy students' self-assessment skills. Am J Pharm Educ. 2007 Oct 15;71(5):89. doi: 10.5688/aj710589.

Exploring older peoples' attitudes and preferences around the use of their healthcare information

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ABSTRACT

AIMS: Routinely collected health data can provide rich information for research and epidemiological monitoring of different diseases, but using the data presents many challenges. This study aims to explore the attitudes and preferences of people aged 55 and over regarding the use of their de-identified health data, and their concerns and comfort in different scenarios.

METHODS: An anonymous online survey was conducted with people aged 55 and over currently engaged with health services in a New Zealand health district during June–October 2022. The survey could be completed online or by telephone and was available in eight languages.

RESULTS: Seventy-nine percent of respondents knew that their health information was currently being used in the ways described in the scenarios, and between 80–87% felt comfortable or very comfortable with their data being used as described in the scenarios. In contrast, 4% (n=9) felt "uncomfortable" or "very uncomfortable" across all of the scenarios. Participants expressed concerns about data accuracy, privacy and confidentiality, security, transparency of use, consent, feedback and the risk of data being sold to commercial companies. Some participants identified situations where permission should be required to link data, including being used by people other than health professionals, containing sensitive health issues, or being used for commercial purposes.

CONCLUSION: This study finds general support from patients for the use of their routinely collected data for secondary purposes as long as its use will benefit the population from which the data are taken. It also highlights the necessity of including the perspectives of different cultures in the collection, storage, use and analysis of health information, particularly concerning Māori cultural considerations.

With new technologies for storage, control and analysis, routinely collected health information has become a valuable tool for researching and developing health services. Utilisation of routinely collected data presents many different challenges, such as the quality of the information, proper management of privacy, ethical use of the information in contexts such as research and development, culturally appropriate use of health data and, in the context of New Zealand, the sovereignty of Māori health data.[1–4]

The use of routinely collected data has facilitated the monitoring of specific health conditions for epidemiological monitoring and improvement of health systems.[5] In New Zealand, analysis of routinely collected national data has been used to develop a clinical risk tool for cardiovascular disease[6] and a virtual diabetes register.[7] In the field of dementia, routinely collected health data have been used to estimate the prevalence of dementia using national datasets; the findings suggested that the prevalence of dementia in Māori and Pacific Island communities is higher than in other ethnic groups.[8] However, community-based dementia prevalence data in New Zealand to test the accuracy of these routinely collected health datasets are scarce.[9] At a more local level, studies using routine health data allow statistical adjustment for potential confounding factors such as comorbidity. These studies suggest there are differences in outcomes for Māori and Pacific Islanders living with dementia (for example, utilisation of dementia services and mortality).[10–13]

Although routinely collected de-identified data can provide valuable knowledge about the epidemiological characteristics of common chronic diseases in New Zealand, these data have tended to be used without individual consent. To date, there has been little research into peoples' opinions about the use and treatment of their health information. In Canada, McCormick et al. (2019) conducted an online survey to compare the opinions of people about the use of routinely collected data for health research and reported that close to 80% of the surveyed people felt positive about the use of that information for research.[14] Similarly, Colombo et al. (2019) conducted a survey to understand the opinions and attitudes of people about using their data in clinical studies in Italy. Thirty-nine percent of the participants approved access to health data to researchers and professionals, and identified important topics, such as data de-identification, secure archives and access agreements, as essential aspects of the sharing models.[15]

In New Zealand, an online survey (Dobson et al., 2021) conducted at Waitematā District Health Board (DHB) investigated patient perspectives, preferences and comfort levels regarding the use of their health data.[16] In the population of inpatients and outpatients they found that more than 80% of participants (aged 16 to 95 years) were comfortable with how de-identified health information was used across various scenarios. However, many stated that they would require the information collected to be accurate and stored securely within the health system, that privacy was maintained, and the data were only used for the public good. They also expressed a preference for improved communication and transparency around how their data were used.

Our research group is interested in exploring whether routinely collected data can be used to predict future decline in brain health and/or dementia and what might be done to promote resilience of brain health. The Lancet Commission for Dementia[17,18] described 12 modifiable risk factors for dementia—in early life (education), in middle age (hearing loss, TBI, hypertension, alcohol and obesity) and in later life (smoking, depression, social isolation, physical inactivity, air pollution, diabetes). Some of these risk factors could be identified using routine health data and would allow the identification of groups of people at higher risk at a population level, which might inform population-level interventions targeted at reducing risk of disease. The prevalence of dementia is rising rapidly due to global demographic ageing and is expected to triple between 2015 and 2050.[19] To date, there is no cure for dementia, so researchers worldwide are attempting to find clinical biomarkers that might provide early identification of people at high risk and hopefully intervene before the onset of irreversible dementia. This is a rapidly developing field, particularly with the growing development of artificial intelligence and machine learning methods for diagnosing and detecting risk factors for various diseases, including dementia, which could be utilised with routinely collected health data.[20–21]

The early identification of decline in brain health is a controversial area, as dementia is still a highly stigmatised disease,[22] and people may not feel comfortable about their health data being used for this purpose, particularly if they fear being identified as being at risk. For that reason, our research group felt that we could not assume that the findings of Dobson et al.[16] (2021) would apply in the specific area of cognitive decline and dementia; thus, we decided to repeat the survey with a focus on brain health.

Our research aimed to explore the attitudes and preferences of people aged 55+ regarding the acceptable use of their de-identified health data and understanding their concerns and comfort in different scenarios related to identification of factors related to cognitive decline and dementia. This would allow New Zealand health institutions and researchers to gain a clearer picture of patients' attitudes and preferences around the use of their de-identified health data in brain health research.

Methods

Participants

People aged 55 and over currently engaged with health services in Te Whatu Ora Counties Manukau were invited to participate in the survey. We chose the cut-off at age 55 because, compared to NZ Europeans, the average age of the onset (or recognition) of dementia is younger for Māori or Pacific peoples living in New Zealand.[10] We included people living with dementia who were known to the Te Whatu Ora Counties Manukau Memory Team and their caregivers. This was done to ensure we had a good representation of people who had lived experience of dementia (either personal or as a caregiver).

The survey sought to gain an understanding of the opinions of older people about the management of their health information, with the following inclusion criteria:

- Currently resident in New Zealand
- Aged 55 years or older
- Currently using health services in Te Whatu Ora Counties Manukau

These criteria were waived for caregivers of a person living with dementia to ensure their inclusion and representation.

Survey design

Our survey was based on the survey constructed by Dobson et al. (2021).[16] A study advisory group with broad representation—including Māori health expertise—drafted questions for Dobson's survey. The research group, advised by Dobson, adapted the original questionnaire for our target population, referencing brain health. We also asked people if they were willing to be individually interviewed (Q13 in the survey) so that we could go into more depth regarding specific issues for Māori and Pacific Islanders.

The survey included a total of 13 questions, assessing:

- Perceptions about the current use of health information by the health service (Te Whatu Ora Counties Manukau) across six different scenarios (mandatory question).
- Perceived comfort with the use of health information on a Likert scale from 1 (very uncomfortable) to 5 (very comfortable) across the same six scenarios, plus one extra (mandatory question).
- Free-text comments about their level of comfort with the use of health information.
- Free-text comments about situations where permission should be sought before their health information was combined with other peoples' to better understand the health of the local population.
- Final comments on the use of health information by Te Whatu Ora Counties Manukau.
- Socio-demographic variables, including year of birth and ethnicity.

All participants received the exact same survey without any randomised items, and adaptive questioning was employed when necessary to minimise the burden on respondents and simplify the complexity of the questions. Also, they could review their answers using the "back button" available in the online questionnaire. The complete survey is available in Appendix 1.

A preliminary survey pilot was conducted to evaluate response times, the relevance of the questions, and the design of the data capture and collection instrument. The final survey was administered in Qualtrics and distributed via an anonymised email link.

In the introduction to the survey, we offered the option of conducting the survey by telephone for those who wished to do so, either in English or in another language: Te Reo Māori, Samoan, Tongan, Mandarin, Cantonese, Hindi or Fijian Hindi.

Ethical approval

This research was approved for three years by Auckland Health Research Ethics Committee AH22266 on 18 October 2021.

Procedures

A link to the online survey was sent by email to outpatients aged 55+ whose email addresses were verified in the Te Whatu Ora Counties Manukau Patient Information Management System (PIMS). The emails were sent to attendees of the Health of Older People outpatient services between 3 January 2019–31 December 2021, including people referred to the memory team, irrespective of the diagnosis made. We invited both patients and their whānau members to be involved in the survey (see survey: Appendix 1). We also specifically invited caregivers of people living with dementia who were current service users of Te Whatu Ora Counties Manukau Memory Team to ensure that their views were included.

Patients (or caregivers of people living with dementia) who wanted to participate but did not wish to complete an online survey were offered the option of an adapted telephone interview. The research assistant conducting the telephone interviews entered the participants' responses into the online survey in real-time, so that responses remained anonymised, and the information was stored in one database. Participation in the study was entirely voluntary, and no rewards or incentives were offered for taking part. Prior to being granted access to complete the survey, participants were requested to provide their consent.

Statistical analysis

The analysis of the survey data was descriptive, using frequency tables and graphs. Due to the potential risk of identifying participants based on the ethnicity question, certain categories were combined using the ethnicity prioritisation method as outlined by Statistics NZ and further elucidated by Yao et al. (2022).[23] This approach was implemented to ensure the protection of participant privacy and confidentiality. The free-text responses were coded using a simple inductive approach identifying common categories and meanings from the data. The analyses were performed in the statistical software R, version 4.2.1.[24]

Results

The survey is reported based on the CHERRIES checklist (Appendix 2).

A total of 326 responses (out of 1,314 emails sent; response rate = 24.8%) were received between 7 June 2022 and 5 October 2022, including 15 from the telephone survey (of which four were completed in Fiji Hindi). Of the responses received, 226/326 (69.3%) were rated as "valid," as they included complete responses to the two mandatory survey questions. No duplicates were identified.

Socio-demographic characteristics

The socio-demographic characteristics of the sample are presented in Table 1. Respondents were mostly NZ European (64.9%), Māori (11.9%) and Asian (10.9%), and their average age was 74.2 (10.6) years. Forty-two percent of the sample knew of a family/whānau member or friend who had been diagnosed with mild cognitive impairment (MCI) or dementia. With respect to caregivers, it is important to note that the responses provided in the data are anonymised, thus precluding the identification of specific individuals in caregiving roles. At least 15 people were caregivers of people living with dementia who were contacted through the Te Whatu Ora Counties Manukau Memory Team. However, 42% of respondents (n=85) reported having a family member or friend living with dementia, so it is reasonable to assume that at least some of these were also caregivers.

Current use of health data

Most participants (179/226, 79.2%) believed that Te Whatu Ora Counties Manukau used their health information in the ways described in all of the six different scenarios (see Figure 1 and Table 2), but up to 15% were unaware that health information from the whole population was combined to look at trends and improve services (scenarios E and F). When we separate this information by whether respondents know a family member/friend living with dementia, the trend does not change. The perception of participants regarding the utilisation of their health data across all proposed scenarios remains independent of having a family member or friend who is living with dementia (See Appendix 3, Table 1).

Level of comfort with use of health information

Figure 2 and Table 3 show that between 79.2 and 86.8% of participants were either comfortable or very comfortable in each of the scenarios proposed (A: 80.2% [n=182], B: 81.9% [n=186], C: 86.8% [n=197], D: 86.3% [n=196], E: 80.1% [n=181], F: 83.2% [n=188] and G: 79.2% [n=179]) and 63.3% [n=143]) felt "comfortable" or "very comfortable" across all seven scenarios. In contrast, less than 10% of the respondents felt uncomfortable or very uncomfortable in each of the scenarios presented (A:7.1%[n=16],B:8.0%[n=18],C:5.3%[n=12],D:5.8% [n=13], E: 8.0% [n=18], F: 7.0% [n=14] and G: 8.4% [n=19]). Four percent (n=9) felt "uncomfortable" or "very uncomfortable" across all of the scenarios. None of the scenarios drew a markedly different response compared to others. Despite the generally high levels of comfort observed (indicated by scores 4 and 5), individuals who have personal knowledge of someone living with dementia exhibit a slight decrease in the frequency of assigning a score of 5 compared to those without such personal connections (see Appendix 3, Table 2).

Free-text comments

Free-text comments about level of comfort and concerns regarding use of personal health data

A total of 54/226 (23.9%) participants commented on their comfort with the use of their health information in the different scenarios. Of those who commented, 57.4% (31/54) felt comfortable with the use of the data in any scenario, although some stated specific conditions for use. Nine respondents (16.7%) were not comfortable, and 14 did not have any relevant comments.

Most expressed the opinion that they were comfortable, provided that health information should be used to improve health services for the local population.

> *"The wonderful care I have received has been informed, and developed, over time, so am happy that anything learnt about me can be used to help others into the future. Win win!"* (Female, 65–74 years, "other" ethnicity)
>
> *"As long as it improves the time it takes to get healthcare"* (Female, 75–84, NZ European)

Participants were also asked if they had any concerns about how Te Whatu Ora Counties Manukau uses their data, and 141/226 (61.9%) free-text responses were obtained. These overlapped with the level of comfort comments and were analysed together. Most people (102/141, 72.3%) stated that they had no concerns, but 27.7% mentioned scenarios in which they would have concerns. These themes are presented in Box 1.

Free-text responses regarding permission to combine data

Sixty-four percent of respondents (144/226) commented on situations where permission would be required before combining health data with other data to better understand the entire population's health. Of the 144, 45.8% (n=66) said that obtaining permission to combine health data was not required in any situation, and 18.8% (n=27) specified it would not be necessary to obtain permission if data were de-identified, stored securely, not shared publicly and handled only by health professionals/researchers. Nineteen respondents (13.2%) said that permission should *always* be obtained to combine the data for any situation, and two respondents (1.4%) commented that, although *a priori* consent was not required, they would like to be informed if their data were used. Nineteen respondents (13.2%) responded that they did not know, or their responses did not correspond to the question asked.

Eleven of the 144 respondents (7.6%) specified other situations where permission should be obtained, for example, if the health information:

- is to be used by people other than health professionals/researchers (n=2)
- contains sensitive health issues or identifiable information (n=5)
- is combined with data from an organisation not related to health (n=1)
- is discussed outside the specific health service that collected it (n=1)
- is used for commercial purposes (n=2)

Discussion

This study found that 79% of the people surveyed knew that Te Whatu Ora Counties Manukau currently used their routinely collected health information in the ways described in the scenarios, and 63% were comfortable or very comfortable with their data being used as described. Approximately 10% were not comfortable with their data being used in the ways described. Participants expressed concerns about the accuracy of data, privacy and confidentiality, security, transparency of use, consent, feedback and the risk of data being sold to commercial companies.

Although the majority of respondents commented that it was not necessary to obtain specific permission for data linkage, there were a range of conditions mentioned that underpinned peoples' comfort with their health information being combined with the health information of others for secondary purposes: data must be anonymous, not shared outside the health service with the public or sold to private companies such as insurers or pharmaceutical companies, and that patients should be informed beforehand about how data will be used.

Our results align with those presented by Dobson et al.,[16] which suggests that older people living in New Zealand have opinions about managing their health data that are similar to that of the wider population. Regarding the current use of health data across the scenarios presented in both Dobson's study and ours, more than 80% of the participants were comfortable or very comfortable with how their data were being used, and less than 10% were uncomfortable or very uncomfortable. Given that the studies had different populations—Dobson's study encompassed a wide age range spanning from 16 to 95 years—while the present study specifically focussed on the opinions and preferences of older individuals with a mean age of 74 years. Additionally, Dobson's study was conducted in Te Whatu Ora Waitematā, whereas the current study took place in Te Whatu Ora Counties Manukau—the finding supports that most people agree with their de-identified data being used for the greater good, as long as key conditions are met around the protection, storage and care of the data. Our findings also coincide with those of Rezaei et al. (2021), who surveyed a sample of healthcare professionals regarding ethical challenges in using health data.[25] The main issues were privacy, autonomy and security. Papoutsi et al. (2015) surveyed patients from primary and secondary care settings in West London (United Kingdom)[26] and found similar concerns about data inaccuracies, prejudice "about sexual or mental health and being labelled as 'hypochondriac' or as having social problems," and potential security and privacy threats; however, the majority of participants were in favour of using data for personal healthcare provision

Table 1: Socio-demographic characteristics of respondents.

		%
Ethnicity (n=202)*	Asian	11
	Māori	12
	NZ European	65
	Pacific	6
	Other	6
Age (n=201)*	<55	4
	55–64	14
	65–74	22
	75–84	47
	>=85	13
Gender (n=202)*	Female	56
	Male	44
Know a family member/friend with dementia or mild cognitive impairment (n=202)*	Yes	42
	No	49
	Don’t know	9

*Completed responses

Table 2: Current use of health information.

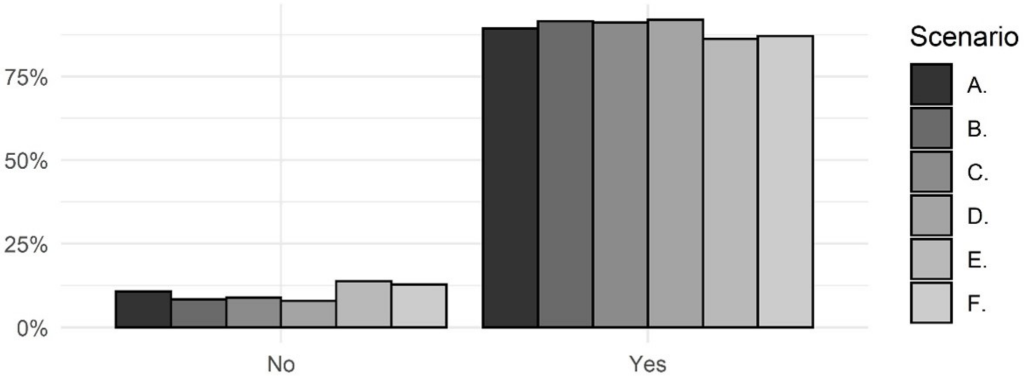
Scenario	**Yes**	**No**	**Total**
A. To make decisions about your healthcare now.	202	24	226
B. To make decisions about your healthcare in the future.	207	19	226
C. To share with other health professionals involved in your care in this organisation.	206	20	226
D. To share with other health professionals involved in your care in other organisations (e.g., your GP, a private hospital, a hospital in another city).	208	18	226
E. To make decisions about improving Counties Manukau services (e.g., combining health information from lots of people to inform and improve the care for other patients using these services in the future).	195	31	226
F. To investigate how to better understand our population and their needs by combining information on our whole population to look at trends (e.g., to investigate how some health conditions could be linked to decline in brain health as we get older and to see how we can help people to keep their brains healthy as they age).	197	29	226

Table 3: Level of comfort for use of health information.

	Level of comfort*					
Scenario	**1** ☹	**2** 🙁	**3** 😐	**4** 🙂	**5** 😃	**Total**
To make decisions about your healthcare now.	15	1	28	50	132	226
To make decisions about your healthcare in the future.	11	7	22	57	129	226
To share with other health professionals involved in your care in this organisation.	9	3	17	58	139	226
To share with other health professionals involved in your care in other organisations (e.g., your GP, a private hospital, a hospital in another city).	10	3	17	61	135	226
To make decisions about improving Counties Manukau health services (e.g., combining health information from lots of people to inform and improve the care for other patients using these services in the future).	10	8	27	56	125	226
To investigate how to better understand our population and their needs by combining information on our whole population to look at trends (e.g., to investigate how some health conditions could be linked to decline in brain health as we get older and to see how we can help people to keep their brains healthy as they age).	10	4	24	63	125	226
To continue to help others even once you have died, or have moved out of our district, where your information continues to be useful and contributes to the full picture for two statements above. This is because removing health information of people can give us an incorrect or incomplete picture of what happened.	14	5	28	57	122	226

*Scale: 1 (very uncomfortable) through to 5 (very comfortable) with how health information is used now.

Figure 1: How people think Te Whatu Ora Counties Manukau currently use their health data.



A. To make decisions about your health care now.

B. To make decisions about your health care in the future.

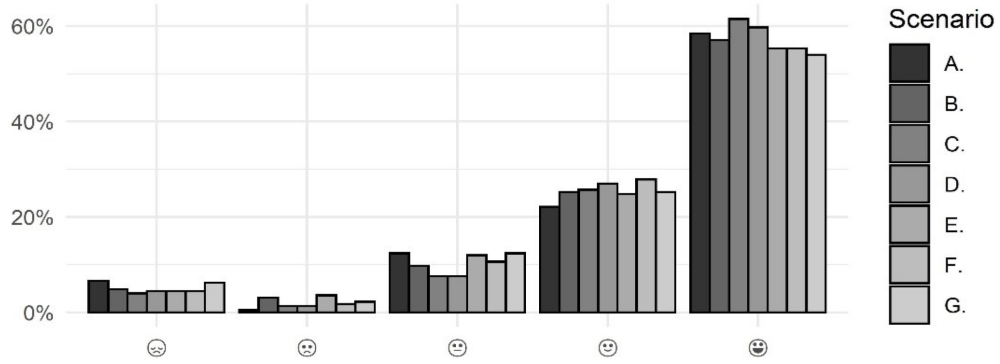
C. To share with other health professionals involved in your care in this organisation.

D. To share with other health professionals involved in your care in other organisations.

E. To make decisions about improving Counties Manukau services.

F. To investigate how to better understand our population and their needs by combining information on our whole population to look at trends.

Figure 2: Comfort level with how Te Whatu Ora Counties Manukau used their health data.



A. To make decisions about your health care now.

B. To make decisions about your health care in the future.

C. To share with other health professionals involved in your care in this organisation.

D. To share with other health professionals involved in your care in other organisations.

E. To make decisions about improving Counties Manukau services.

F. To investigate how to better understand our population and their needs by combining information on our whole population to look at trends

G. To continue to help others even once you have died or have moved out of our district where your information continues to be useful and contributes to the full picture for two statements above.

Box 1: Areas of concern regarding the use of routinely collected health data.

Accuracy of data

"*My concern would be, how often is your information up to date and current? How transparent is your procedure in how you gather the information, and are your procedures authentic and culturally responsive to elderlies from all ethnicities?*" (Female, 75–84, Pacific)

"*Data can be incorrectly put into a computer … imperfect humans can have their own agenda*." (Female, 75–84, NZ European)

Privacy and confidentiality

"*Security of my name etc. being linked to my health conditions, as I regard this as a priority and only to be shared with the health officials. I assume that there is adequate protection/process to ensure patient details are totally kept confidential. I have nothing to hide but it is information about myself which I would only want used in the healthcare environment.*" (Male, 55–64, NZ European)

How the data are used

"*I don't believe basing your decisions about my healthcare now or in the future should solely be based on what you have on the data base you hold*." (Female, 75–84, Pacific)

"*In my experience, unless you speak to people concerned directly, too much information is taken out of context distorting facts. Medical records are exceptionally bad for this*." (Female, 55–64, NZ European)

"*Grouping people for statistics and planning is one thing, but for actual delivery of medicine the individual must always be front and centre. As with any group of people, older people can be stereotyped, and this does not necessarily lead to the best individual health outcomes*." (Female, 65–74, NZ European)

Consent to use data and feedback on how health information has been used

"*I would like them to ring me up first before using/sharing my data*." (Female, 65–74, Māori)

"*It would be nice to get feedback on how my information has helped collaboratively to create/determine/understand health of, specifically, my population*." (Female, 65–74, Māori)

Use of data from deceased patients

"*Once I am passed my specific information dies with me*." (Male, 55–64, Māori)

"*Not to use my personal health information after I am gone, only for my immediate family*." (Female, 55–64, Māori)

Data being sold to private companies

"*As long as there is no sell out—you know how modern technology can sometimes do weird things and make mistakes. Whether it's a machine/human error, as long as it's been protected*." (Female, 75–84, Pacific)

"*(Not) In situations where it will be used for marketing purposes*." (Female, >85, Asian)

(89.7%), for health services policy and planning (79.5%), or for research (81.4%). The authors concluded that public participation and transparency are the pillars to establish the limits of the information to be shared and how researchers and medical personnel should access the data.[26]

A limitation of our study is the generalisability of the results. According to the 2018 population census,[27] the distribution of ethnicity in the Counties Manukau population aged 65+ was 7% Māori, 12% Pacific Islanders, 20% Asian and 60% NZ European. The ethnic breakdown of our sample was partially representative of the local population (12% Māori, 6% Pacific Islanders, 11% Asian and 65% NZ European), but the small sample size did not allow us to fully explore inter-ethnic differences in responses. In addition, about 25% of patients in the Te Whatu Ora Counties Manukau Memory Team have verified email addresses, contributing to the under-representation of different ethnicities in the responses. To address this issue, alternative sampling techniques should be implemented to ensure a more comprehensive representation of all ethnicities.

For Māori people, data should be considered as taonga, which relates to the idea that data are owned collectively by one or more whānau and are covered by rights, with obligations for active protection of that power by the Crown.[28] Further work is required to delve deeper into the use of healthcare information and the implications for Māori Data Sovereignty, the inherent rights and interests that Māori have in relation to the collection, ownership and application of Māori data.[29] It was notable that several Māori respondents did not agree to their data being used after their death, because one tikanga perspective is that the deceased are tapu and items belonging to the deceased are to be destroyed.[30] More work needs to be done to address Māori data concerns, particularly post-mortem data, which are important predictors of mortality and need to be analysed in research. Such concerns might indicate that IT-system design needs to be considered to reflect a culturally responsive system that aligns with the use of routinely collected health data relevant to examination of mate wareware (dementia) from a Māori perspective.[31] Current health IT systems are not designed to give patient control over the use of their data (for example, to opt out of research that is deemed not culturally appropriate). Adequately addressing cultural considerations with respect to data use may place demands on IT systems for greater patient control over their data and effective consent mechanisms for the use of their data.

The results of our study suggest that health services need to reflect on how best to use and protect peoples' health data—a rich resource—while also respecting peoples' rights to say how their data are used. Our findings are a first step towards describing older peoples' opinions about how to use their health data for health research around brain health. The next phase of the study will focus on conducting more in-depth individual interviews to gain a deeper understanding of peoples' opinions in different scenarios regarding the use of their health data. This could be particularly relevant for Māori, Pacific Island and Asian communities, who may possess distinct perspectives that differ from the majority of the survey sample, which predominantly was NZ European (65%).

Conclusion

Our findings indicate that these respondents are supportive of their health information being used for secondary purposes to benefit others, but there are conditions/limitations to this comfort that researchers need to consider, ensuring they use health information in a patient-informed way. It also highlights the necessity of including the perspectives of different cultures in the collection, storage, use and analysis of health information, particularly with respect to Māori cultural considerations.

COMPETING INTERESTS

Nil.

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REFERENCES

1. Kalkman S, van Delden J, Banerjee A, et al. Patients' and public views and attitudes towards the sharing of health data for research: a narrative review of the empirical evidence. J Med Ethics. 2022 Jan;48(1):3-13. doi: 10.1136/medethics-2019-105651.
2. Mursaleen LR, Stamford JA, Jones DA, et al. Attitudes towards data collection, ownership and sharing among patients with Parkinson's disease. J Parkinsons Dis. 2017;7(3):523-531. doi: 10.3233/JPD-161045.
3. NICE Citizens Council. What ethical and practical issues need to be considered in the use of anonymised information derived from personal care records as part of the evaluation of treatments and delivery of care? [Internet]. London: National Institute for Health and Care Excellence (NICE); 2015 Nov 11. Citizens Council Reports No. 18.
4. Health Research Council of New Zealand. Guidelines for Researchers on Health Research involving Māori [Internet]. Auckland: Health Research Council of New Zealand; 2010 [cited 27 Mar 2023]. Available from: https://www.hrc.govt.nz/resources/guidelines-researchers-health-research-involving-maori.
5. Jorm L. Routinely collected data as a strategic resource for research: priorities for methods and workforce. Public Health Res Pract. 2015 Sep 30;25(4):e2541540. doi: 10.17061/phrp2541540.
6. Pylypchuk R, Wells S, Kerr A, et al. Cardiovascular disease risk prediction equations in 400 000 primary care patients in New Zealand: a derivation and validation study. Lancet. 2018 May 12;391(10133):1897-1907. doi: 10.1016/S0140-6736(18)30664-0.
7. Te Whatu Ora – Health New Zealand. Virtual Diabetes Register: Technical Guide [Internet]. Wellington: Te Whatu Ora – Health New Zealand; 2022 [cited 16 Mar 2023]. Available from: https://www.tewhatuora.govt.nz/publications/virtual-diabetes-register-technical-guide/.
8. Cheung G, To E, Rivera-Rodriguez C, et al. Dementia prevalence estimation among the main ethnic groups in New Zealand: a population-based descriptive study of routinely collected health data. BMJ Open. 2022 Sep 7;12(9):e062304. doi: 10.1136/bmjopen-2022-062304.
9. Ma'u E, Cullum S, Yates S, et al. Dementia Economic Impact Report 2020 [Internet]. Auckland: The University of Auckland,; 2021 [cited 12 Dec 2022]. Available from: https://cdn.alzheimers.org.nz/wp-content/uploads/2021/09/Dementia-Economic-Impact-Report-2020.pdf.
10. Cullum S, Mullin K, Zeng I, et al. Do community-dwelling Māori and Pacific peoples present with dementia at a younger age and at a later stage compared with NZ Europeans? Int J Geriatr Psychiatry. 2018 Aug;33(8):1098-1104. doi: 10.1002/gps.4898.
11. Cullum S, Varghese C, Yates S, et al. Predictors of Aged Residential Care Placement in Patients Newly Diagnosed with Dementia at a New Zealand Memory Service. J Long Term Care. 2021;0(2021):24-32. doi: 10.31389/jltc.46.
12. Cullum S, Varghese C, Coomarasamy C, et al. Predictors of mortality in Māori, Pacific Island, and European patients diagnosed with dementia at a New Zealand Memory Service. Int J Geriatr Psychiatry. 2020 May;35(5):516-524. doi: 10.1002/gps.5266.
13. Ma'u E, Saeed F, Yates S, et al. Do Māori and Pacific Peoples Living with Dementia in New Zealand Receive Equitable Long-Term Care Compared with New Zealand Europeans? J Long Term Care. 2022;0(2022):222-233. doi: 10.31389/jltc.148.
14. McCormick N, Hamilton C, Koehn CL, et al. Canadians' views on the use of routinely collected data in health research: a patient-oriented

cross-sectional survey. CMAJ Open. 2019 Apr 4;7(2):E203-E209. doi: 10.9778/cmajo.20180105.

15. Colombo C, Roberto A, Krleza-Jeric K, et al. Sharing individual participant data from clinical studies: a cross-sectional online survey among Italian patient and citizen groups. BMJ Open. 2019 Feb 19;9(2):e024863. doi: 10.1136/bmjopen-2018-024863.
16. Dobson R, Whittaker R, Wihongi H, et al. Patient perspectives on the use of health information. N Z Med J. 2021 Dec 17;134(1547):48-62.
17. Livingston G, Sommerlad A, Orgeta V, et al. Dementia prevention, intervention, and care. Lancet. 2017 Dec 16;390(10113):2673-2734. doi: 10.1016/S0140-6736(17)31363-6.
18. Livingston G, Huntley J, Sommerlad A, et al. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. Lancet. 2020 Aug 8;396(10248):413-446. doi: 10.1016/S0140-6736(20)30367-6.
19. Prince MJ, Wimo A, Guerchet MM, et al. World Alzheimer Report 2015. The Global Impact of Dementia: An analysis of prevalence, incidence, cost and trends [Internet]. London: Alzheimer’s Disease International (ADI); 2015 Aug [cited 16 Mar 2023]. Available from: https://www.alzint.org/u/WorldAlzheimerReport2015.pdf.
20. Jammeh EA, Carroll CB, Pearson SW, et al. Machine-learning based identification of undiagnosed dementia in primary care: a feasibility study. BJGP Open. 2018 Jun 13;2(2):bjgpopen18X101589. doi: 10.3399/bjgpopen18X101589.
21. Kumar S, Oh I, Schindler S, et al. Machine learning for modeling the progression of Alzheimer disease dementia using clinical data: a systematic literature review. JAMIA Open. 2021 Aug 2;4(3):ooab052. doi: 10.1093/jamiaopen/ooab052.
22. Lynch C. World Alzheimer Report 2019: Attitudes to dementia [Internet]. London: Alzheimer’s Disease International (ADI); 2020 [cited 17 Mar 2023]. Available from: https://www.alzint.org/u/WorldAlzheimerReport2019.pdf.
23. Yao ES, Meissel K, Bullen P, et al. Demographic discrepancies between administrative-prioritisation and self-prioritisation of multiple ethnic identifications. Soc Sci Res. 2022 Mar;103:102648. doi: 10.1016/j.ssresearch.2021.102648.
24. R Core Team. R: A Language and Environment for Statistical Computing [Internet]. Vienna: R Foundation for Statistical Computing; 2022 [cited 16 Jan 2023]. Available from: https://www.R-project.org/
25. Rezaei M, Jafari-Sadeghi V, Cao D, Mahdiraji HA. Key indicators of ethical challenges in digital healthcare: A combined Delphi exploration and confirmative factor analysis approach with evidence from Khorasan province in Iran. Technol Forecast Soc Change. 2021;167:120724. doi: 10.1016/j.techfore.2021.120724.
26. Papoutsi C, Reed JE, Marston C, et al. Patient and public views about the security and privacy of Electronic Health Records (EHRs) in the UK: results from a mixed methods study. BMC Med Inform Decis Mak. 2015 Oct 14;15:86:1-15. doi: 10.1186/s12911-015-0202-2.
27. Lees J, Lee M, Winnard D. Demographic Profile: 2018 Census, Population of Counties Manukau [Internet]. Auckland: Counties Manukau Health; 2021 [cited 30 May 2023]. Available from: https://www.countiesmanukau.health.nz/assets/About-CMH/Performance-and-planning/health-status/Demographic-profile-2018-Census-Population-of-Counties-Manukau.pdf.
28. Wilson D. Māori Data Sovereignty and the WAI 2522 Report: A summary of some Māori Data Sovereignty insights from the WAI 2522 Report on the Comprehensive and Progressive Agreement for Trans-Pacific Partnership (CPTPP). Auckland: The University of Auckland; 2022 [cited 14 Feb 2023].
29. Te Mana Raraunga. What is Māori Data Sovereignty? [Internet]. New Zealand: Te Mana Raraunga; 2023 [cited 27 Mar 2023]. Available from: https://www.temanararaunga.maori.nz/
30. Mead HM. Tikanga Māori: Living by Māori values. Wellington: Huia Publishers; 2016.
31. Dudley M, Menzies O, Elder H, et al. Mate wareware: Understanding ‘dementia’ from a Māori perspective. N Z Med J . 2019 Oct 4;132(1503):66-74.

Appendices

Appendix 1: Counties Manukau DHB* survey on use of your health information.

We warmly invite patients and their whānau members aged 55 and over using the Counties Manukau DHB Memory Service or other older peoples' health services to take a short survey on how their health information is used by the DHB.

The following information will help you decide whether you would like to take part.

What is the aim:

The aim of this survey is to improve our understanding of how people want Counties Manukau to use their health information and their concerns about how it is used. We would like to check what you think about how we currently use your health information, and what we should and should not do with it in the future.

We have a particular interest in using health information to explore whether some health conditions might contribute to a decline in brain health as we get older. So, we are asking people who have recently been seen by the Memory Service and/or other older peoples' health services in Counties Manukau, and their whānau/family members.

Who has authorised this study and who is undertaking it:

This research was approved for three years by Auckland Health Research Ethics Committee AH22266 on 18/10/21. The study is being undertaken by researchers at the University of Auckland and Counties Manukau Health. The study is funded by the New Zealand Health Research Council.

Researchers:

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What are you being asked to do?

- Your participation in this survey is totally your choice and voluntary.
- When you click on the link below you are indicating your consent to take part in this study.
- The survey is anonymous so once you have finished and clicked on the submit button you cannot withdraw your information from the study.
- By taking part in this survey you are indicating that you:
    - have read this information
    - live in New Zealand
    - are 55 years of age or more
    - are currently using an older peoples' health service at CMDHB and/or you are a whanau member of someone using the service
- If you do agree to take part, you may stop answering questions at any time.
- Whether or not you participate in this survey, and your response if you do, will not in any way impact on the care you are receiving from your healthcare team.
- The survey should take you about 10 minutes to complete.

What will be done with the information from this survey?

The survey information will be stored securely at The University of Auckland for 10 years and then destroyed according to The University of Auckland research code of conduct guidelines.

Your name will not be recorded on the survey. No information that could personally identify you will be used in any report from this survey. We will combine the anonymous responses from all participants for analysis.

The results will be presented at conferences and published in a research journal. The findings of the survey will be shared with the funders of this study and also with the staff at Counties Manukau.

Appendix 1 (continued): Counties Manukau DHB* survey on use of your health information.

Telephone survey option

If you would prefer to take this anonymous survey by telephone either in English or in another language (eg., Te Reo Māori, Samoan, Tongan, Mandarin, Cantonese, Hindi, or Fijian Hindi) we may be able to help you. Whichever way you choose it will be confidential—your answers will be entered on to the anonymous survey but not your name.

Thank you for taking time to read about this study. Thank you in advance for taking part and helping to increase our understanding of how our patients want us to use their health information.

By clicking on the next button to begin the survey you are indicating that you consent to take part in this study.

** Counties Manukau DHB is the previous name for the health service, now renamed Te Whatu Ora Counties Manukau, which is how it is referred to in the article*

START SURVEY

Health information is any information that we collect about you during your visit. This information is used to guide your treatment and may be shared with your GP (general practitioner) for your ongoing care.

We would like to check what you think about how we currently use your **health information**, and what we should and should not do with it in the future.

There are a number of terms used in this survey, this is what they mean:

Healthcare = any services provided to you by health professionals (in hospitals, clinics, primary care, community centres, at home)

Older peoples' health services = any health services provided for older people

Health information = is any information regarding your health, or any health or disability services provided to you. This could include information such as appointment times, health conditions/illnesses, demographic information (e.g., age, gender, ethnicity), and test information (e.g., blood results, brain scans).

Health professional = Any person that is involved in providing you with healthcare services e.g., doctor, nurse, physiotherapist, radiographer.

Q1 Considering the **health information** (e.g., information about your age, gender, ethnicity, diagnosis, tests, treatments) that Counties Manukau collects about you, do you think that we are using this health information:*

		Yes	**No**
a	To make decisions about your healthcare now.	○	○
b	To make decisions about your healthcare in the future.	○	○
c	To share with other health professionals involved in your care in this organisation.	○	○
d	To share with other health professionals involved in your care in other organisations (e.g., your GP, a private hospital, a hospital in another city).	○	○
e	To make decisions about improving Counties Manukau services (e.g., combining health information from lots of people to inform and improve the care for other patients using these services in the future).	○	○

Appendix 1 (continued): Counties Manukau DHB* survey on use of your health information.

	f	To investigate how to better understand our population and their needs by combining information on our whole population to look at trends (e.g., to investigate how some health conditions could be linked to brain health as we get older and to see how we can help people to keep their brains healthy as they age).	○	○

Q2	How comfortable do you feel with your health information being used in the following ways on a scale from 1 to 5 where 1 is “**very uncomfortable**” and 5 is “**very comfortable**”:*						
			1	**2**	**3**	**4**	**5**
			☹	🙁	😐	🙂	😃
	a	To make decisions about your healthcare now.	○	○	○	○	○
	b	To make decisions about your healthcare in the future.	○	○	○	○	○
	c	To share with other health professionals involved in your care in this organisation.	○	○	○	○	○
	d	To share with other health professionals involved in your care in other organisations (e.g., your GP, a private hospital, a hospital in another city).	○	○	○	○	○
	e	To make decisions about improving CM-DHB health services (e.g., combining health information from lots of people to inform and improve the care for other patients using these services in the future).	○	○	○	○	○
	f	To investigate how to better understand our population and their needs by combining information on our whole population to look at trends (e.g., to investigate how some health conditions could be linked to brain health as we get older and to see how we can help people to keep their brains healthy as they age).	○	○	○	○	○
	g	To continue to help others even once you have died or have moved out of our district where your information continues to be useful and contributes to the full picture for (e) and (f) above. This is because removing health information of people can give us an incorrect or incomplete picture of what happened.	○	○	○	○	○

Appendix 1 (continued): Counties Manukau DHB* survey on use of your health information.

Q3	You can make any comments on your level of comfort on any of the above uses of health information here:
Q4	In which situations would you want us to get your permission before we combine your data with other peoples' to better understand the health of our population?
Q5	Do you have any further concerns about how we (Counties Manukau) look after or use your health information?
The following questions are about you so we can look at patterns in responses to this survey and to make sure a range of people have completed the survey: **(The following questions are optional)**	
Q6	Which year were you born? (e.g., 1954) Year:
Q7	What is your gender? ☐ Male ☐ Female ☐ Another gender
Q8	Which suburb do you normally live in? (e.g., Māngere, Papakura, Howick)
Q9	Which ethnic group do you belong to? Mark the box or boxes which apply to you. ☐ NZ European ☐ Māori ☐ Samoan ☐ Cook Island Māori ☐ Tongan ☐ Niuean ☐ Chinese ☐ Indian ☐ Other such as Dutch, Japanese, Tokelauan. Please state:

Appendix 1 (continued): Counties Manukau DHB* survey on use of your health information.

Q10	Are you descended from a Māori (that is, did you have a Māori birth parent, grandparent, or great-grandparent, etc)? ☐ Yes ☐ Don't know ☐ No	
	Q10a	Do you know the name(s) of your iwi (tribe or tribes)? ☐ Yes ☐ No
	Q10b	Give the name(s) and region(s) of your iwi (tribe or tribes): Iwi: Region: Iwi: Region: Iwi: Region: Iwi: Region:
Q11	If you live in New Zealand but were not born here, answer this question. Which year did you first arrive to live in New Zealand? (e.g., 1974) Year:	
Q12	Do you have a family/whānau member or friend who has been diagnosed with mild cognitive impairment (MCI) or dementia? (yes/no) ☐ Yes ☐ No ☐ I don't know	
Q13	We are hoping to talk to some people about the issues in this survey in more detail, either face-to-face or online, using Zoom. If you click on the "yes" button, you will be directed to a separate database which is not connected to this survey—your answers to the survey will still remain anonymous. We will contact you in a few months to see if you are still interested. There is no obligation to participate, and you are free to change your mind. Are you interested in participating in the next phase of the study? If you click on the yes button, you will be redirected to a separate database after you click on the submit button below. ☐ Yes ☐ No	
Thank you for taking the time to complete this survey.		

Appendix 2: Checklist for reporting results of internet e-surveys (CHERRIES).

Item category	Checklist item	Explanation
Design	Describe survey design	A consecutive sample of people who are aged 55 and over, currently resident in New Zealand, engaged with health services in Te Whatu Ora Counties Manukau, and have a verified email address. We included people living with dementia who were known to the Te Whatu Ora Counties Manukau Memory Team and their caregivers.
Institutional Review Board (IRB) approval and informed consent process	IRB approval	This research was approved for three years by Auckland Health Research Ethics Committee AH22266 on 18 October 2021.
	Informed consent	Participant information was presented in the first part of the survey document. After they read the information, we presented a button: “by clicking on the next button to begin the survey, you are indicating that you consent to take part in this study.”
	Data protection	The survey did not ask for personal information. Every answer was completely anonymous.
Development and pre-testing	Development and pre-testing	The survey was adapted from Dobson et al. (2021). The changes were discussed with the research team and Advisory Group. The survey was carried out on Qualtrics, and we conducted two pilot studies: the first one within the research team and the second with volunteers from a population similar to the target population.
Recruitment process and description of the sample having access to the questionnaire	Open survey versus closed survey	This was a closed survey. We sent the link to the questionnaire via email to people who met the inclusion criteria.
	Contact mode	The initial contact with the potential participants was through verified email addresses held on file by Te Whatu Ora Counties Manukau.
	Advertising the survey	We did not advertise the survey.
Survey administration	Web/email	The link to the survey was sent out through email. The link was generated from Qualtrics, and the responses were stored in the Qualtrics database.
	Context	NA—a website was not used for our survey
	Mandatory/voluntary	This was a voluntary survey. We sent out the link to the list of email addresses, and they answered voluntarily.
	Incentives	No incentives.
	Time/date	7 June 2022–5 October 2022

Appendix 2 (continued): Checklist for reporting results of internet e-surveys (CHERRIES).

Item category	Checklist item	Explanation
Survey administration	Randomisation of items or questionnaires	We did not randomise the items.
	Adaptive questioning	Yes, conditional to Q10: are you descended from a Māori (that is, did you have a Māori birth parent, grandparent, or great-grandparent, etc.)? We displayed Q10a: do you know the name(s) of your iwi (tribe or tribes)? if they selected “yes”. Likewise, we displayed Q10b: give the name(s) and region(s) of your iwi (tribe or tribes) if they selected “yes” in Q10a.
	Number of items	Page 1: presentation of the survey. Page 2: one question (Q1). Page 3: two questions (Q2, Q3). Page 4: two questions (Q4, Q5). Page 5: seven questions (Q6–Q12). Page 6: one question (Q13).
	Number of screens (pages)	Six.
	Completeness check	Q1 and Q2 were mandatory. They were highlighted as mandatory, and the respondent could not continue the survey without first answering those two questions. The others were non-mandatory. For Q10: are you descended from a Māori (that is, did you have a Māori birth parent, grandparent, or great-grandparent, etc)? and Q12: do you have a family/whānau member or friend who has been diagnosed with mild cognitive impairment (MCI) or dementia? we offered the option “I don’t know.”
	Review step	Respondent could review their answers using the back button in the questionnaire.
Response rates	Unique site visitor	Qualtrics associated every response with an IP address. We used the IP address to identify if the respondent was unique. We did not have duplicates.
	View rate (ratio of unique survey visitors/unique site visitors)	NA
	Participation rate (ratio of unique visitors who agreed to participate/unique first survey page visitors)	326/326

Appendix 2 (continued): Checklist for reporting results of internet e-surveys (CHERRIES).

Item category	Checklist item	Explanation
Response rates	Completion rate (ratio of users who finished the survey/users who agreed to participate)	226/326 completed the two mandatory questions and were considered the "valid" sample.
Preventing multiple entries from the same individual	Cookies used	NA
	IP check	Qualtrics associated every response with an IP address. We used the IP address to identify if the respondent was unique. We did not have duplicates.
	Log file analysis	NA
	Registration	Respondents could leave the survey and finish later. We were able to monitor that from the Qualtrics control. When the period of the survey finished, we collected all the incomplete surveys.
Analysis	Handling of incomplete questionnaires	As Q1 and Q2 were the two mandatory survey questions, we only analysed information from those surveys that had completed the two mandatory questions (n=226). The other questions were optional, so we had some missing data. We reported the number of responses and missing data in the paper.
	Questionnaires submitted with an atypical timestamp	We evaluated the time stamps for the 226 "valid" responses and did not find any atypical ones. On average, respondents took 55 minutes to answer the survey, including people that stopped and came back later to finish the survey.
	Statistical correction	We did not apply any statistical correction for non-response.

Appendix 3: Knowledge and comfort level of respondents by whether the respondent has a family member/friend living with dementia.

Appendix 3, Table 1: How people think Te Whatu Ora Counties Manukau currently use their health data by whether the respondent has a family member/friend living with dementia.

		Knowing family member/friend with dementia		
Scenario		**Yes (n=85)**	**No (n=99)**	**Don't know (n=18)**
A. To make decisions about your healthcare now.	Yes	92%	92%	67%
	No	8%	8%	33%
B. To make decisions about your healthcare in the future.	Yes	93%	92%	83%
	No	7%	8%	17%
C. To share with other health professionals involved in your care in this organisation.	Yes	89%	94%	89%
	No	11%	6%	11%
D. To share with other health professionals involved in your care in other organisations (e.g., your GP, a private hospital, a hospital in another city).	Yes	92%	94%	89%
	No	8%	6%	11%
E. To make decisions about improving Counties Manukau services (e.g., combining health information from lots of people to inform and improve the care for other patients using these services in the future).	Yes	84%	90%	83%
	No	16%	10%	17%
F. To investigate how to better understand our population and their needs by combining information on our whole population to look at trends (e.g., to investigate how some health conditions could be linked to decline in brain health as we get older and to see how we can help people to keep their brains healthy as they age).	Yes	86%	88%	83%
	No	14%	12%	17%

Appendix 3, Table 2: Comfort level with how Te Whatu Ora Counties Manukau used their health data by whether the respondent has a family member/friend living with dementia.

		Knowing family member/friend with dementia		
Scenario		**Yes (n=85)**	**No (n=99)**	**Don’t know (n=18)**
To make decisions about your healthcare now.	1☹	8%	6%	0%
	2🙁	1%	0%	0%
	3😐	13%	6%	22%
	4🙂	22%	19%	17%
	5😃	55%	69%	61%
To make decisions about your healthcare in the future.	1☹	6%	5%	0%
	2🙁	4%	4%	0%
	3😐	14%	5%	17%
	4🙂	25%	20%	17%
	5😃	52%	66%	67%
To share with other health professionals involved in your care in this organisation.	1☹	5%	4%	0%
	2🙁	1%	2%	0%
	3😐	7%	4%	11%
	4🙂	34%	16%	22%
	5😃	53%	74%	67%
To share with other health professionals involved in your care in other organisations (e.g., your GP, a private hospital, a hospital in another city).	1☹	5%	5%	0%
	2🙁	2%	1%	0%
	3😐	6%	6%	17%
	4🙂	31%	22%	11%
	5😃	56%	66%	72%
To make decisions about improving Counties Manukau health services (e.g., combining health information from lots of people to inform and improve the care for other patients using these services in the future).	1☹	5%	5%	0%
	2🙁	5%	3%	0%
	3😐	12%	7%	22%
	4🙂	27%	23%	6%
	5😃	52%	62%	72%

Appendix 3, Table 2 (continued): Comfort level with how Te Whatu Ora Counties Manukau used their health data by whether the respondent has a family member/friend living with dementia.

		Knowing family member/friend with dementia		
Scenario		**Yes (n=85)**	**No (n=99)**	**Don't know (n=18)**
To investigate how to better understand our population and their needs by combining information on our whole population to look at trends (e.g., to investigate how some health conditions could be linked to decline in brain health as we get older and to see how we can help people to keep their brains healthy as they age).	1 ☹	6%	4%	0%
	2 🙁	0%	3%	0%
	3 😐	8%	8%	11%
	4 🙂	34%	21%	17%
	5 😃	52%	64%	72%
To continue to help others even once you have died or have moved out of our district where your information continues to be useful and contributes to the full picture for two statements above. This is because removing health information of people can give us an incorrect or incomplete picture of what happened.	1 ☹	8%	6%	0%
	2 🙁	2%	1%	0%
	3 😐	9%	10%	22%
	4 🙂	29%	22%	11%
	5 😃	51%	61%	67%

Low and intermediate risk aortic dissection detection risk score and negative D-dimer: a word of caution

Steve W F R Waqanivavalagi

ABSTRACT

A low or intermediate aortic dissection detection risk score coupled with a negative D-dimer has been proposed as a reliable rule-out strategy for acute aortic syndrome (AAS) in the emergency department. Locally, its use has crept into the work-up of patients with suspected AAS. This opinion piece offers a word of caution—the stakes are high for missing AAS. Although the rule-out strategy does show exciting potential, it remains to be validated, especially for Australasian patients. Patients with suspected AAS should continue to be investigated with timely advanced imaging such as contrast-enhanced computed tomographic aortography.

Acute aortic syndrome (AAS) comprises acute aortic dissection, intramural haematoma and penetrating aortic ulcer. Together with aortic rupture and aortic embolus, AAS remains a life-threatening vascular emergency for emergency department (ED) patients presenting with chest, back or abdominal pain.

AAS is often difficult to diagnose in the ED because of its non-specific clinical presentations and relatively low incidence. There are also no validated rule-out strategies. Thus, for patients in whom AAS is being considered, diagnostic imaging must be undertaken, which is usually with contrast-enhanced computed tomographic aortography (CTA). However, CTA remains limited by access issues and concerns around contrast nephropathy and contrast anaphylaxis. EDs are also becoming increasingly busy, leading to delays in obtaining timely scans. Such delays can have important clinical consequences for patients waiting in the ED with undiagnosed AAS.

Local experiences of catastrophic outcomes contributed to by delayed imaging led to a recent retrospective cohort study of all CTAs performed in the ED at Auckland City Hospital, between 2009–2019, for the work-up of AAS.[1] Waqanivavalagi et al. observed that, during the 11-year study period, there were 135 (8.2%) cases of at least one AAS diagnosis and 220 (13.4%) cases where an alternative diagnosis was made. During the study period, thoracic CTA use for investigating suspected AAS increased. Although the annual incidence of AAS did not increase, it remained higher than reported in overseas institutions.

In 2010, the American Heart Association and American College of Cardiology released guidelines for the diagnosis and management of patients with thoracic aortic disease, including 12 high-risk clinical features to assist in the early detection of AAS. Rogers et al. examined patients enrolled in the International Registry of Acute Aortic Dissection between 1996–2009 and evaluated the number of patients with confirmed AAS who presented with at least one of the 12 clinical parameters.[2] An aortic dissection detection risk score (ADD-RS) from zero–three was then calculated based on the presence of any high-risk clinical feature from any of the three high-risk categories (**Table 1**). It was observed that, of 2,538 patients with AAS, 2,430 (95.7%) had at least one high-risk clinical feature. Increasing ADD-RS scores were also found to correlate with an increasing incidence of AAS. Thus, it was suggested that the ADD-RS may play a useful role in risk-stratifying AAS.

Suzuki et al. investigated the role of D-dimer, a biomarker used to exclude deep vein thrombosis and pulmonary embolism, in the exclusion of AAS.[3] They conducted a prospective multicentre study of 220 patients suspected of having AAS, of whom 87 were diagnosed with AAS and 133 with other diagnoses. D-dimer was markedly elevated in patients with AAS using a cut-off value of 500 ng/mL, with a negative likelihood value of 0.07 throughout the first 24 hours. Suzuki et al. thus concluded that D-dimer may be useful in risk-stratifying patients with AAS in the first 24 hours of symptom onset.

Nazerian et al. combined a low or intermediate risk ADD-RS (<1) with a negative D-dimer in their multicentre prospective observational study of patients presenting with any of: chest/abdominal/back pain, syncope, or perfusion deficit, and suspected AAS.[4] Of 1,850 patients included in the study, 924 patients had an ADD-RS <1 and negative D-dimer, of whom three were positive for AAS. This yielded a failure rate of 0.3%.

In 2020, Bima et al. systematically reviewed studies integrating the ADD-RS with D-dimer.[5] Four articles met their inclusion criteria, including the prospective study by Nazerian et al. and three retrospective studies with methodological limitations.[4,6–8] Despite the study limitations, Bima et al. observed negligible heterogeneity and consistently high sensitivity of an ADD-RS <1 with negative D-dimer, thus concluding that the rule-out test may be reliably used.[5]

Bhat et al. evaluated the efficacy of D-dimer in ruling our AAS in low and intermediate risk patients undergoing CTA for the Auckland cohort.[9] They observed that, during the 11-year study period, 14.3% (236/1,646) of CTAs were preceded by a serum D-dimer. A subsequent negative D-dimer result had a sensitivity of 100% (95% CI: 66–100%) and negative predictive value of 100% (95% CI: 97–100%) for ruling out AAS in low and intermediate risk patients. It was also shown that the annual number of D-dimer requests increased significantly during the study period (p=0.0059 using the Mann–Kendall trend test), which likely resulted from a significant rise in the number of negative (p=0.0036), rather than positive (p=0.15), D-dimer results. It was highlighted that there were no missed cases of AAS in patients with a negative D-dimer who were at low or intermediate risk for AAS. The authors concluded that a D-dimer <500 ng/mL might be useful in reducing CTA-use in patients at low or intermediate risk presenting with suspected AAS.

In saying this, an ADD-RS <1 coupled with a negative D-dimer as a rule-out strategy for AAS remains to be validated.[1,10] It is also plausible that the 12 high-risk clinical features comprising the ADD-RS are not sufficiently sensitive for AAS in the New Zealand population. Bhat et al. analysed the Auckland cohort of patients through an ethnic lens and observed that the age-standardised AAS incidence per 100,000 ED presentations was significantly higher in Māori (6.9) and Pacific Islanders (5.3) than patients of other ethnicities (2.3).[10] Despite the higher incidence, disproportionately fewer CTAs were requested in the ED for Māori (9.2 CTAs per AAS diagnosis) and Pacific Islanders (9.2 CTAs per AAS diagnosis) than for patients of other ethnic groups (13.8 CTAs per AAS diagnosis). Thus, it was recommended that the increased risk of AAS in Pacific Islander and Māori patients be considered by clinicians when investigating AAS. Similar inequities were observed by Xu et al. in Waikato.[11]

It has previously been observed that the three- to four-fold higher incidence of AAS among Māori, when compared with non-Māori, is associated with higher incidences of thoracic aortic aneurysms, use of cigarettes and vascular risk factors.[12] This higher incidence of AAS makes it especially notable both that an AAS registry does not presently exist within New Zealand and that there are few, if any, prospective studies that include New Zealand patients.

Despite all the benefits of a rule-out strategy for AAS, it appears that the ADD-RS and negative D-dimer pathway is not yet appropriate for local emergency physicians to rely upon in the ED. Indeed, the stakes are high, and missing even one case of AAS will likely have serious consequences for the patient, the patient's next of kin and for the treating doctor. It may be prudent for governing bodies to monitor the progress of high-risk rule-out strategies such as the ADD-RS and D-dimer pathway and then endorse its use once a satisfactory evidence base is available to justify it.

Locally, the ADD-RS and D-dimer pathway has crept into the work-up of suspected AAS on an *ad hoc* basis. Indeed, there is increasing evidence that suggests the pathway may soon play an important role in risk-stratifying patients with suspected AAS. However, given that the pathway remains to be validated, its utility in New Zealand patients remains to be explored, and the potential for patient harm in missed cases is extremely high. It is suggested that, for patients in whom AAS is being considered, ADD-RS and D-dimer rule-out is not undertaken, but advanced imaging is instead performed in a timely fashion. Establishment of an AAS registry and a well-designed, prospective study of the ADD-RS and D-dimer pathway are two important next steps to validating the pathway for patients with suspected AAS in New Zealand.

Table 1: The high-risk clinical features of the aortic dissection detection risk score spread across three high-risk categories: high-risk pain conditions, high-risk pain features and high-risk exam features.

Finding		**Points**
Any high-risk condition	Marfan syndrome	1 point
	Family history of aortic disease	
	Known aortic valve disease	
	Recent aortic manipulation	
	Known thoracic aortic aneurysm	
Any high-risk pain feature	Chest, back or abdominal pain described as any of the following:	1 point
	Abrupt onset	
	Severe intensity	
	Ripping or tearing	
Any high-risk exam feature	Evidence of perfusion deficit (pulse deficit, systolic BP differential or focal neurological deficit in conjunction with pain)	1 point
	New murmur of aortic regurgitation (with pain)	
	Hypotension or shock state	

COMPETING INTERESTS

Nil.

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REFERENCES

1. Waqanivavalagi SW, Bhat S, Schreve F, et al. Trends in computed tomography aortography and acute aortic syndrome in an emergency department within Aotearoa New Zealand. Emerg Med Australas. 2022 Oct;34(5):769-778. doi: 10.1111/1742-6723.13974.
2. Rogers AM, Hermann LK, Booher AM, et al. Sensitivity of the aortic dissection detection risk score, a novel guideline-based tool for identification of acute aortic dissection at initial presentation. Circulation. 2011 May 24;123(20):2213-8. doi: 10.1161/CIRCULATIONAHA.110.988568.
3. Suzuki T, Distante A, Zizza A, et al. Diagnosis of acute aortic dissection by D-dimer: the International Registry of Acute Aortic Dissection Substudy on Biomarkers (IRAD-Bio) experience. Circulation. 2009 May 26;119(20):2702-7. doi: 10.1161/CIRCULATIONAHA.108.833004.
4. Nazerian P, Mueller C, Soeiro AM, et al. Diagnostic Accuracy of the Aortic Dissection Detection Risk Score Plus D-Dimer for Acute Aortic Syndromes: The ADvISED Prospective Multicenter Study. Circulation. 2018 Jan 16;137(3):250-258. doi: 10.1161/CIRCULATIONAHA.117.029457.
5. Bima P, Pivetta E, Nazerian P, et al. Systematic Review of Aortic Dissection Detection Risk Score Plus D-dimer for Diagnostic Rule-out Of Suspected Acute Aortic Syndromes. Acad Emerg Med. 2020 Oct;27(10):1013-1027. doi: 10.1111/acem.13969.
6. Nazerian P, Morello F, Vanni S, et al. Combined use of aortic dissection detection risk score and D-dimer in the diagnostic workup of suspected acute aortic dissection. Int J Cardiol. 2014 Jul 15;175(1):78-82. doi: 10.1016/j.ijcard.2014.04.257.
7. Gorla R, Erbel R, Kahlert P, et al. Accuracy of a diagnostic strategy combining aortic dissection detection risk score and D-dimer levels in patients with suspected acute aortic syndrome. Eur Heart J Acute Cardiovasc Care. 2017 Aug;6(5):371-378. doi: 10.1177/2048872615594497.
8. Kotani Y, Toyofuku M, Tamura T, et al. Validation of the diagnostic utility of D-dimer measurement in patients with acute aortic syndrome. Eur Heart J Acute Cardiovasc Care. 2017 Apr;6(3):223-231. doi: 10.1177/2048872616652261.
9. Bhat S, Bir S, Schreve F, et al. D-dimer with the aortic dissection detection risk score may improve patient selection for acute aortic syndrome diagnostic imaging. Forthcoming 2023.
10. Bhat S, Bir S, Schreve F, et al. Ethnic Disparities in CT Aortography Use for Diagnosing Acute Aortic Syndrome. Radiol Cardiothorac Imaging. 2022 Nov 17;4(6):e220018. doi: 10.1148/ryct.220018.
11. Xu W, Mani K, Khashram M. Ethnic differences in incidence and outcomes of acute aortic syndromes in the Midland region of New Zealand. J Vasc Surg. 2022 Feb;75(2):455-463.e2. doi: 10.1016/j.jvs.2021.08.066.
12. Waqanivavalagi SWFR. Acute Aortic Syndrome in Aotearoa New Zealand: What Does It Mean for Māori? Curr Probl Cardiol. 2023 May;48(5):101594. doi: 10.1016/j.cpcardiol.2023.101594.

Recurrent Takotsubo syndrome with variable echocardiographic and electrocardiographic appearances

Aleisha Easton, Andrew J Kerr, Jen-Li Looi

Takotsubo syndrome (TS) (also known as apical ballooning syndrome) is characterised by acute but usually rapidly reversible left ventricular (LV) dysfunction with distinct wall motion abnormalities.[1,2] The condition tends to occur in postmenopausal women after a stressful event. Recurrent TS is not uncommon and can exhibit variations in triggering factors and ventricular wall motion patterns.[3,4] We describe a case in which the pattern of regional wall motion and the associated ECG changes differed between the first and the recurrent admission.

Case report

A 61-year-old Māori woman with a previous history of TS presented with chest pain, dyspnoea and elevated troponin T (175ng/L [normal range: 0–15]). Electrocardiogram (ECG) on arrival showed sinus rhythm with no ischaemic changes and a prolonged QTc of 498msec (Figure 1A). Given her multiple cardiac risk factors of hypertension, hyperlipidaemia and family history of premature coronary artery disease, coronary angiography was performed and revealed trivial coronary artery disease. Transthoracic echocardiogram (TTE) demonstrated hyperdynamic LV apex with relative hypokinesis of the basal segments and preserved systolic function, suggestive of reverse or basal TS (Figure 1B, Video 1 [please contact the corresponding author for video files]). There was no identifiable pre-event stressor despite specific enquiry after the diagnosis was made. Repeat TTE 3 months later showed complete resolution of wall motion abnormalities.

Fourteen years ago, she presented with similar complaints with no identifiable stressor. ECG on arrival showed widespread deep T-wave inversion and a prolonged QTc of 480msec (Figure 1C). Coronary angiography revealed normal coronary arteries. TTE showed moderate systolic impairment with akinesis of the apex, consistent with apical TS (Figure 1D, Video 2 [please contact the corresponding author for video files]). Follow-up TTE showed normalisation of cardiac function and resolution of wall motion abnormalities.

Discussion

Our patient presented many years ago with apical TS and an ECG that showed widespread deep T-wave inversion with a prolonged QTc interval. Because of this prior TS diagnosis, the clinical team were suspicious that the current presentation was a case of recurrent TS. However, they were uncertain about the diagnosis because the ECG did not show the deep T-wave inversion or the apical akinesis seen at the index admission. However, the ECG did show QTc interval prolongation, which is typical of TS, and review of the echo identified the reverse variant. Clinicians should understand that both the pattern of wall motion abnormality and ECG changes can vary markedly between presentations in the same patient. They should also be aware that TS can recur many years later.

TS mimics acute coronary syndrome (ACS) but has a distinct pathophysiology. Four different echocardiographic variants of TS have been described, including apical, mid-ventricular, basal/reverse and focal types.[2,5] A fifth variant of TS has also been described recently where the mid-left ventricle is hyperdynamic but the apex and base are akinetic or hypokinetic (reverse mid-ventricular Takotsubo).[6] Several ECG features of TS have been reported that may help to differentiate TS from an ACS, including absence of reciprocal changes, absence of abnormal Q-waves, progressive QTc interval prolongation and widespread T-wave inversion.[7]

Recurrence of TS is not an uncommon phenomenon. The incidence of TS recurrence is estimated to range from 4.7% to 5% at long-term follow-up.[4,8] The variation in echocardiographic variants between index and recurrent TS events in some patients has been previously described.[8,9] This observation cannot be explained by the hypothesised pathophysiological causal mechanisms. The variability in the pattern of wall motion abnormality between episodes casts doubt on the hypothesis that the observed regionality is related to variation in beta-receptor density and sensitivity.[10]

Another hypothesis is that a previous episode of TS may protect the previously affected region in the TS recurrence, with a higher vulnerability of other regions.[11] However, previous reports have described recurrent cases of TS with the same ventricular wall motion pattern, similar to the index event.[4]

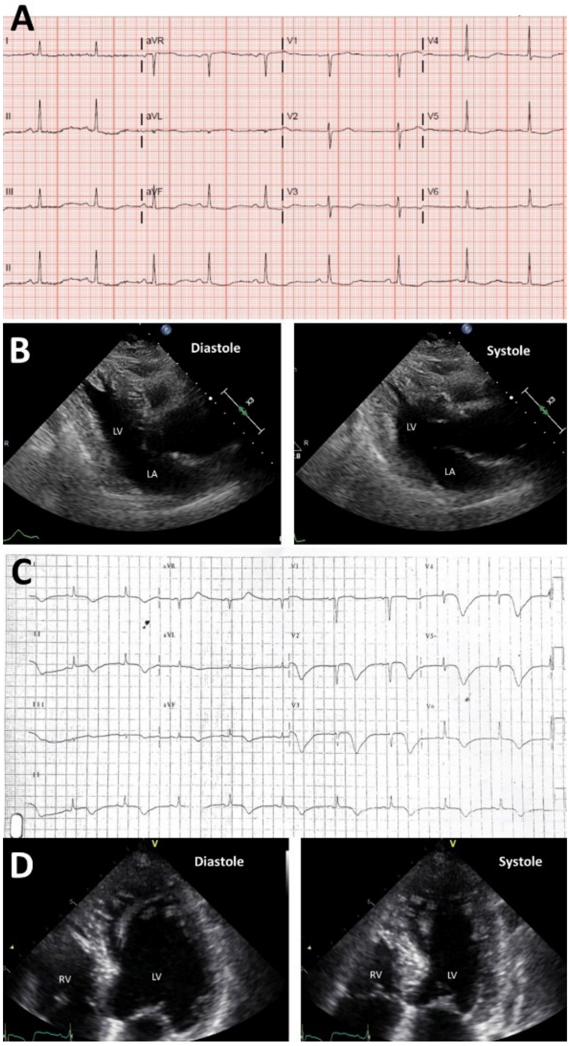
To our knowledge the variation in ECG pattern we observed between recurrent events with differing echocardiographic variants has not previously been described and should be further investigated. Further study is required to clarify the aetiology of this novel condition and identify effective preventive strategies.

Figure 1: A. Electrocardiogram (ECG) on admission demonstrated normal sinus rhythm with no ischaemic changes and prolonged QTc.

B. Echocardiography showed akinesis of the basal segments and hypercontractility of the mid to apical segments of the left ventricle consistent with basal or reverse type of Takotsubo syndrome.

C. ECG 14 years ago showed global giant T-wave inversions with prolonged QTc.

D. Echocardiography 14 years ago showed akinesis of the mid to apical segments and hypercontractility in the basal segments of the left ventricle consistent with apical type of Takotsubo syndrome.



LV = left ventricle; LA = left atrium; RV = right ventricle

COMPETING INTERESTS

Nil.

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REFERENCE

1. Parodi G, Del Pace S, Carrabba N, et al. Incidence, clinical findings, and outcome of women with left ventricular apical ballooning syndrome. Am J Cardiol. 2007;99(2):182-5. doi: 10.1016/j.amjcard.2006.07.080.
2. Templin C, Ghadri JR, Diekmann J, et al. Clinical Features and Outcomes of Takotsubo (Stress) Cardiomyopathy. N Engl J Med. 2015;373(10):929-38. doi: 10.1056/NEJMoa1406761.
3. Madias JE. Comparison of the first episode with the first recurrent episode of takotsubo syndrome in 128 patients from the world literature: Pathophysiologic connotations. Int J Cardiol. 2020;310:27-31. doi: 10.1016/j.ijcard.2020.03.003.
4. El-Battrawy I, Santoro F, Stiermaier T, et al. Incidence and Clinical Impact of Recurrent Takotsubo Syndrome: Results From the GEIST Registry. J Am Heart Assoc. 2019;8(9):e010753. doi: 10.1161/JAHA.118.010753.
5. Ghadri JR, Wittstein IS, Prasad A, et al. International Expert Consensus Document on Takotsubo Syndrome (Part I): Clinical Characteristics, Diagnostic Criteria, and Pathophysiology. Eur Heart J. 2018;39(22):2032-46. doi: 10.1093/eurheartj/ehy076.
6. Bridgman PG, Chan CW. The fifth takotsubo variant. Echocardiography. 2017;34(1):122-3. doi: 10.1111/echo.13405.
7. Looi JL, Wong CW, Lee M, et al. Usefulness of ECG to differentiate Takotsubo cardiomyopathy from acute coronary syndrome. Int J Cardiol. 2015;199:132-40. doi: 10.1016/j.ijcard.2015.07.046.
8. Kato K, Di Vece D, Cammann VL, et al. Takotsubo Recurrence: Morphological Types and Triggers and Identification of Risk Factors. J Am Coll Cardiol. 2019;73(8):982-4. doi: 10.1016/j.jacc.2018.12.033.
9. Ghadri JR, Jaguszewski M, Corti R, et al. Different wall motion patterns of three consecutive episodes of takotsubo cardiomyopathy in the same patient. Int J Cardiol. 2012;160(2):e25-7. doi: 10.1016/j.ijcard.2012.01.021.
10. Akashi YJ, Nef HM, Lyon AR. Epidemiology and pathophysiology of Takotsubo syndrome. Nat Rev Cardiol. 2015;12(7):387-97. doi: 10.1038/nrcardio.2015.39.
11. Xu B, Williams PD, Brown M, Macisaac A. Takotsubo cardiomyopathy: does recurrence tend to occur in a previously unaffected ventricular wall region? Circulation. 2014;129(7):e339-40. doi: 10.1161/CIRCULATIONAHA.113.007015.

Claim against Dr. Frazerhurst

NZMJ, 1923

The hearing of the action for damages brought by Margaret Alice Huyton (Mr. Singer), wife of Richard William Huyton, shipwright and carpenter, of Whangarei, against Dr. J. L. Frazerhurst (Mr. Northcroft), of Kaikohe, on the ground of alleged negligence in the performance of a surgical operation known as the Cæsarean, which plaintiff underwent at the Whangarei Hospital in September, 1920, a swab being left in the patient, came before Mr. Justice Stringer and a special jury on 27th June, 1923.

His Honour, in summing up, said that no doubt the case was a most important one and would require very careful consideration. The jury was asked to give judgement on a practice which had been adopted for a very long period by the greatest surgeons in the world. In the first place it was necessary for the jury not to be influenced by sympathy for the plaintiff. Their duty was to ascertain whether defendant had been guilty of negligence in connection with this operation. So far as he could judge, His Honour stated, defendant had taken all reasonable precautions and it could hardly be said that he was lax in following the practice adopted by all surgeons of note. A point to consider was whether or not the surgeons were the best qualified to testify as to what was the best in the interests of everyone. It would be an unwarrantable assumption to say that surgeons made these rules purely for their own protection. They were the best qualified to determine what were the proper precautions to take. One could hardly conceive surgeons adopting a system which they had not found to be the best both for themselves and their patients. Defendant followed the regular system, which was followed by the most eminent surgeons in the world, and, so far as he could see, all steps had been taken with scrupulous care. As long as there was the human element there then there would always be a possibility of a mistake being made. In this operation speed was absolutely essential, as plaintiff had been in labour for about thirty hours and nature had refused to relieve her in the normal way and she was therefore in a collapsed condition and it was important that she be removed from the operating-table at the earliest possible moment. The longer plaintiff remained on the operating-table the greater the shock and the less chance of recovery. All these factors were urging the surgeon to be as quick as possible. Otherwise plaintiff may have collapsed and died. All sorts of difficulties may present themselves to a surgeon as he goes along, and steps have to be taken to prevent them interfering with the operation. It seemed that if a surgeon kept a count of the swabs himself, he would be very likely to lose count of the swabs during the operation, and might disagree with the nurse as to the number of swabs that had been put in and the delay in searching for the supposed missing swab might prove disastrous.

The matron who assisted at this operation and the swab nurse were trained people, and they knew the absolute necessity of recovering everything that was put into the body. If they were there for that particular purpose, was it unreasonable that they should be trusted to devote their attention and knowledge to that particular function, so that the surgeon might not be distracted from other parts of the operation? It seemed to him, His Honour continued, that the jury were asked to say that this was a wrong system and that the duty of the surgeon was to count the swabs himself. If this was done the surgeon’s attention would be distracted from the patient and the results might be most serious. The suggestion that two swabs had been treated as one would account for the mistake. The swabs were of varying thicknesses, and if two thin swabs were put into the body as one, with only one tape visible, and covered with blood, water, etc., when the swab was taken out one would remain behind. The counting by the surgeon would then be useless. He would have to inspect each swab first. The jury had to decide whether or not the defendant had used reasonable care, and whether or not he was at fault in following the practice adopted by all noted surgeons.

The verdict was for the defendant, Dr. Frazerhurst.