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IN THIS ISSUE:

EDITORIAL

Supporting safer screen behaviours: new recommendations for children and adolescents

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Contents

Editorial

Articles

Viewpoints

Clinical correspondence

100 years ago in the *NZMJ*

Summaries

Impacts of digital technologies on child and adolescent health: recommendations for safer screen use in educational settings

Julie Cullen, Alex Muntz, Samantha Marsh, Lorna Simmonds, Jan Mayes, Keryn O'Neill, Scott Duncan

Kids in New Zealand use screens more than most kids around the world. While screens can provide opportunities for learning and fun, excessive use can have health risks, like harming eyes and physical health. Our review shows that using screens for more than 2 to 6 hours a day can be risky, a time that young New Zealanders can exceed with educational screen use alone. The UN has called for urgent talks to manage screen use in schools to balance benefits and harms. New recommendations endorsed by The Paediatric Society of New Zealand and others aim to help kids use screens in a safer way, maximising the opportunities that digital technologies can offer, with lower risk.

Emergent inequity of glycaemic metrics for Māori children with type 1 diabetes is negated by early use of continuous glucose monitoring

Luke A Stedman, Jonathan Williman, Mercedes Burnside, Hannah Davies, Craig Jefferies, Brooke Marsters, Ryan Paul, Benjamin Wheeler, Esko Wiltshire, Martin de Bock, on behalf of KIWIDIAB

We studied whether continuous glucose monitoring (CGM) could improve blood glucose outcomes for children with type 1 diabetes (T1D) within 12 months of diagnosis and reduce disparities based on ethnicity or socio-economic status (SES). We looked at data from 206 children under 15 years old in Aotearoa New Zealand and found that fewer Māori children used CGM compared to European children, partially due to SES differences. Children with lower SES also had poorer blood glucose control. However, CGM use helped lessen the gap in blood glucose levels between Māori and European children. Our study suggests that using CGM within 12 months of diagnosis may help address ethnic and SES disparities in T1D outcomes by improving blood glucose control and ensuring equitable access to the technology.

Examining the approaches used to assess decision-making capacity in healthcare practice

Nicola Hickling, Clare M McCann, Lynette Tippett, Gary Cheung

This article is the first to examine in detail the tools and approaches currently being used to assess decision-making capacity in New Zealand. This is important because previous research has shown that approaches vary widely. We also found wide variance in the assessment approach among those conducting and those involved in decision-making capacity assessments. A structured clinical interview was the approach used by a third of those conducting these assessments, while just over a quarter of this same group reported not being aware of this approach. Quality and consistency were reported to be lacking, knowledge around partial capacity was poor and supported decision making was often overlooked for substitute decision making. There is an urgency to this area of clinical practice with clinicians requesting the development of a nationally recognised standard that is adhered to by all involved in decision-making capacity assessments.

Written information about retinopathy of prematurity in Aotearoa New Zealand: identification, review and opportunities for improvement

Holly White, Lisa Kremer, Liza Edmonds, Amber Young

There are multiple resources available to whānau in neonatal intensive care units across the country. According to our results, whānau may not be provided with sufficient written information so they are fully informed about the retinopathy of prematurity (ROP) eye examination.

Audit of diabetes-related lower extremity amputations in the Northern Region of New Zealand 2013–2016

Michele Garrett, Sarah Gray

This study looked at lower limb amputations occurring in people with diabetes living in the Northern Region of New Zealand. We found that more men than women had amputations. Amputations were more common for Māori and Pacific peoples and people living in higher deprivation. Many people hadn't seen a specialist podiatrist (foot specialist) in the 3 months prior to amputation. This suggests that more work is needed to improve outcomes for people at greater risk of amputation and improve access to podiatry care.

Epidemiology and diagnostic challenges of anti-NMDAR encephalitis: a study from the Waikato region

Pablo Richly, Beatriz Romero Ferrando

This study looked at cases of anti-NMDA receptor encephalitis, a type of brain inflammation caused by the body's own antibodies attacking NMDA receptors in the brain. The researchers reviewed 10 years of antibody testing data at Waikato Hospital in New Zealand. Out of 318 patients tested, only 10 had positive antibody results, and just six of those were actually diagnosed with anti-NMDA receptor encephalitis after further evaluation. Since confirmed cases were relatively rare, the authors suggest considering tighter criteria for approving this expensive antibody test when autoimmune psychosis is suspected but typical brain inflammation symptoms are not present.

Prevalence of urinary incontinence in New Zealand women from the cross-sectional Sexual and Reproductive Health module of the New Zealand Health Survey 2014/2015

Mark Weatherall, Jean Hay-Smith, Don Wilson

Urinary incontinence is the complaint of involuntary leakage of urine. Urinary incontinence is common in women, and this was studied in a New Zealand national health survey in 2014 and 2015. The results from this survey have not been published until now. The survey found that four in 10 New Zealand women have incontinence. This is more common for older women, women who have had one or more children, and in women with increased body size. Incontinence was just as likely in Māori compared to non-Māori after accounting for these factors.

Modern paradigms in biologic sequencing of inflammatory bowel disease in Aotearoa

Michael Chieng, Bronson Marshall, Caroline Jiang

Our paper serves as a practical guide for healthcare providers who prescribe biologic and advanced therapies to patients with inflammatory bowel disease (IBD). It outlines the latest evidence-based research and recommendations for selecting the most suitable therapies for patients based on individual-specific factors. It aims to support healthcare staff in making informed decisions that align with current clinical standards and promotes a collaborative approach across disciplines and regions through the framework of Health New Zealand – Te Whatu Ora.

Dying well in Aotearoa New Zealand for ethnic minority communities: a time for reclamation?

Shamsul Shah, Shanthi Ameratunga, Roshini Peiris-John, Rodrigo Ramalho, Tess Moeke-Maxwell, Paul Wolffram

To live and to die well are universal aspirations. However, evidence suggests that most New Zealanders

are likely to die in hospital or in aged residential care. Furthermore, there are reported unjust variations in end-of-life care experienced by ethnic minority communities overseas. Despite increasing proportions of people identifying with Asian, Middle Eastern, Latin American and African ethnicities in Aotearoa New Zealand, local data, research and policies addressing their needs at end-of-life are few. Acknowledging this invisibility, we argue for the need to partner with ethnic minority communities to create culturally safe end-of-life care health services, and to adopt a public health approach that can support people of ethnic minority communities at the end-of-life to die well.

A rare case of severe constrictive pericarditis post-COVID requiring pericardiectomy

Mark O Pottier, Emily R Hill, John G Lainchbury, Ian G Crozier

This case report describes a rare complication of COVID-19 known as constrictive pericarditis (development of severe heart failure caused by a stiffening of the outer layer surrounding the heart). This was removed surgically, which resulted in marked improvement. This case outlines the important features that were initially missed on echocardiogram (imaging of the heart).

Impacts of digital technologies on child and adolescent health: recommendations for safer screen use in educational settings

Julie Cullen, Alex Muntz, Samantha Marsh, Lorna Simmonds, Jan Mayes, Keryn O'Neill, Scott Duncan

ABSTRACT

The use of screen-based digital technologies (such as computers and digital devices) is increasing for children and adolescents, worldwide. Digital technologies offer benefits, including educational opportunities, social connection and access to health information. Digital fluency has been recognised as an essential skill for future prosperity. However, along with these opportunities, digital technologies also present a risk of harm to young people. This issue may be particularly important for young New Zealanders, who have among the highest rates of screen use in the world. Our recently published review examined the impacts of digital technologies on the health and wellbeing of children and adolescents. Key findings revealed some positive impacts from moderate use of digital technologies; however, frequent and extended use of screen-based digital tools were associated with negative impacts on child and adolescent health in some areas, such as eye health, noise-induced hearing loss and pain syndromes. Conversely, in areas such as mental health, wellbeing and cognition, quality of screen media content and additional factors such as age may be more important than duration of use. These challenges gave us the impetus to develop pragmatic recommendations for the use of digital technologies in schools, kura kaupapa and early childhood education. Recommendations include interventions to lower risk across different ages and stages of development. Supporting young people to mitigate risk and develop safer screen behaviours will allow them to gain essential digital skills and access opportunities that will enable them to thrive.

The use of screen-based digital technologies, such as computers and smartphones, is increasing for children and adolescents across the globe. Within education settings, this increased focus comes as a response to a fast-changing world. Digital technologies have advanced more quickly than any other innovation in history, with access and mastery of digital tools now recognised as being essential for future prosperity.[1] However, along with opportunities for learning, access to health information and other benefits, there is broad agreement among the scientific community that digital devices and internet access also present a risk of harm to young people.[2] This can be through exposure to inappropriate and harmful content, risks to privacy and security,[3] and with frequent and extended use, negative impacts to health, wellbeing and educational outcomes.[2,4] We therefore believe there is an urgent need to provide schools with evidence-based recommendations for their safer use.

In our role as practitioners and researchers in the field of paediatric health/wellbeing (including national and international subject experts), we have a responsibility to protect and promote the rights of children. This includes their rights in a digital world, which often does not have their safety and best interests at heart.[1,5]

While acknowledging the need for young people to access and master digital technologies, these risks have more recently been recognised by the United Nations. The United Nations Educational, Scientific and Cultural Organization (UNESCO) has noted that educational screen use can contribute to risks of excessive screen use for young people.[4] Both the competing interests and growing influence of the educational technology industry have been recognised as a cause for concern, noting that the pull of commercial interests can be in the opposite direction of children's educational and health needs.[1,4] The United Nations Special Rapporteur has called for urgent discussion and regulation of the digitisation of education, including for potential risks to health and development (among others), and the necessary prerequisites of children's capacities

and skills in education before developing digital competencies.[1]

These issues may be particularly important for young people in Aotearoa New Zealand, who have among the highest rates of screen use in the world, both at home and school.[5] Organisation for Economic Co-operation and Development (OECD) data found that worldwide, screen use increased from 21 to 35 hours per week for adolescents between 2012 and 2018. For Aotearoa New Zealand youth, screen use increased from 22 hours to 42 hours in the same period. Students in Aotearoa New Zealand have the highest use of internet in class in the world, and among the highest use of digital devices in class in the world, including from young ages.[5,6]

Issues of equity around children and digital technologies are complex, with the focus to date primarily being on barriers to access for prioritised communities. Technology can offer benefits for Indigenous people and prioritised students, and in accordance with the Universal Declaration of Human Rights, everyone has the right to share in scientific advancement and its benefits.[1,7] Yet while the digital divide for Māori appears to be shrinking, a potential new equity issue has arisen. Screen use is now significantly higher for Māori children and children from low socio-economic communities than other groups.[8,9] Māori adolescents have the second highest internet use after Asian youth and are the most predominant group with internet use in excess of 6 hours per day.[10] Therefore, children and adolescents from prioritised communities may be at greater risk of harms associated with excessive screen use.

These challenges gave us the impetus to develop pragmatic recommendations for the use of digital technologies in schools, kura kaupapa and early childhood education (see **Table 1**).[11] The purpose of these recommendations is to allow young people to benefit from the opportunities digital technologies afford while simultaneously protecting them from avoidable harms. The recommendations focus on evidence-based advice for safer screen behaviours in education settings, across different ages and stages of development. Recommendations include interventions to lower risk, such as advice on eye breaks, safer use of headphones/earbuds, ergonomics and lighting, and screen time limits or a balance of screen and non-screen learning tasks (depending on the age of the young person).

This document summarises 2 years of work, involving analysis of evidence and consultation. While not exhaustive, a substantial narrative review with a systematic search strategy was undertaken, to allow a holistic overview needed for decision-making, given the topic breadth.[12] We described and explored current evidence on the positive and negative impacts of digital technologies on the health and wellbeing of children and adolescents across eight areas: vision, hearing, obesity, pain, sleep, cognition, mental health and social impacts. Opportunities for further research to better understand these challenges were highlighted. This review focussed on large-scale

Table 1: Excerpt from *Recommendations for the use of digital technologies: schools, kura and early childhood education.*

0 to 6 years	
Restrict	No screen use for under 2-year-olds No screen use in ECE settings without approval from teacher or kaiako
Limit	Minimal screen use for over 2-year-olds If choosing to use screens, maximum session length 10 to 15 minutes Limit headphone/earbud use
Encourage	Purposeful and intentional use, co-viewing advised Outdoor exercise and free-play Reward prosocial and positive learning behaviours with social interactions or physical activities, rather than screen-based activities Correct ergonomics and lighting

Table 1 (continued): Excerpt from *Recommendations for the use of digital technologies: schools, kura and early childhood education.*

6 to 12 years	
Restrict	No smartphone/smartwatch access during class unless exempt No screen use in class without approval from teacher or kaiako
Limit	Up to a third of the school day learning on screens (limited use for younger students with gradual increase reflecting age/development), unless required for students with special learning needs Session length 20 minutes Limit headphone/earbud use
Encourage	Purposeful and intentional use of devices in schools only Outdoor exercise/activities Protect play in break periods (screen free, outdoors if possible) Reward prosocial and positive learning behaviour with social interactions or physical activities, rather than screen-based activities Adjustable seating and chairs Correct ergonomics and lighting Paper homework option preferred Education on healthy screen behaviours Continue to educate students about digital citizenship and cyber security

13 to 18 years	
Restrict	No smartphone/smartwatch access during class unless exempt
Limit	Eye breaks every 20 minutes of screen use, or change task Limit headphone/earbud use
Encourage	Purposeful and intentional use of devices in schools only Balance of screen and non-screen learning tasks Outdoor exercise/activities Reward prosocial and positive learning behaviours with social interactions or physical activities, rather than screen-based activities Adjustable seating and chairs Correct ergonomics and lighting Paper homework option if task allows Education on healthy screen behaviours Continue to educate students about digital citizenship and cyber security

Table 1: Excerpt from *Recommendations for the use of digital technologies: schools, kura and early childhood education*.[11] Adapted from: Cullen J, Muntz A, Marsh S, et al. Recommendations for the use of digital technologies: schools, kura and early childhood education. 2024. Available from: https://www.paediatrics.org.nz/knowledge-hub/view-resource?id=59

studies (with sample sizes including thousands of participants), systematic reviews and meta-analyses. Smaller studies were considered due to the large heterogeneity across disciplines, in areas of health where limited evidence was available.

Key findings revealed some positive impacts from moderate use of digital technologies; however, frequent and excessive use of screen-based digital tools were associated with negative impacts to child and adolescent health and wellbeing. We also noted that the definition of excessive use was difficult to establish, although the majority of harms in the review were found with total daily screen use of between 2 and 6 hours per day.

While debate continues around the importance of quality versus quantity of screen use, our review found more nuanced results. Total duration of screen time per day was found to impact eye health (myopia and dry eye disease), noise-induced hearing loss (NIHL) through headphone/earbud use and pain syndromes regardless of content, through mechanisms of use and/or the displacement of behaviours that would promote health. Conversely, the quality of screen media content is important and may be more relevant than duration of screen use, for child and adolescent mental health, wellbeing and cognition, with additional confounding factors including age/developmental stage and other variables.

Sustainable solutions regarding digital technologies require a balance of children's rights to health, education and internet access. *Recommendations for the use of digital technologies: schools, kura and early childhood education* were based on findings from our review, existing international guidelines/legislation and input from subject experts. In developing these recommendations, consultation was sought with education stakeholders, industry, experts in health and education, and relevant government ministries, including collaboration with different sectors who have different perspectives and goals. They have been reviewed and endorsed by The Paediatric Society of New Zealand, The New Zealand Pasifika Principals Association (NZPP), Brainwave Trust Aotearoa, The Office of Early Childhood Education and others.

Digital technologies are changing the way we live in society and ensuring that they provide opportunities to our young people, contribute to equity and do not cause harm will require a multi-pronged approach for caregivers, educators and policy makers. Pragmatic recommendations aimed at educational institutions that can shape children's digital environments call attention to these challenges and offer actionable solutions. Supporting young people to mitigate risk and develop safer screen behaviours will allow them to gain essential skills and access opportunities that will enable them to thrive.

COMPETING INTERESTS
Nil.

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Emergent inequity of glycaemic metrics for Māori children with type 1 diabetes is negated by early use of continuous glucose monitoring

Luke A Stedman, Jonathan Williman, Mercedes Burnside, Hannah Davies, Craig Jefferies, Brooke Marsters, Ryan Paul, Benjamin Wheeler, Esko Wiltshire, Martin de Bock, on behalf of KIWIDIAB

ABSTRACT

AIM: We investigated if continuous glucose monitoring (CGM) in children with type 1 diabetes (T1D) within 12 months of being diagnosed modifies the development of glycaemic outcome inequity on the basis of either ethnicity or socio-economic status (SES).

METHOD: De-identified clinical and SES data from the KIWIDIAB data network were collected 12 months after diagnosis in children under 15 years diagnosed with T1D between 1 October 2020 and 1 October 2021.

RESULTS: There were 206 children with new onset T1D: CGM use was 56.7% for Māori and 77.2% for Europeans. Mean (SD) HbA1c was 62.4 (14.2) mmol/mol at 12 months post diagnosis, but Māori were 9.4mmol/mol higher compared to Europeans (p<0.001). For those without CGM, Māori had an HbA1c 10.8 (95% CI 2.3 to 19.4, p=0.013) mmol/mol higher than Europeans, whereas there was no evidence of a difference between Māori and Europeans using CGM (62.1 [9.3] mmol/mol vs 58.5 [12.4] mmol/mol p=0.53 respectively). Comparing quintiles of SES, HbA1c was 10.8 (95% CI 4.7 to 16.9, p<0.001) mmol/mol higher in the lowest quintile of SES compared to the highest.

CONCLUSION: These observational data suggest CGM use ameliorates the ethnic disparity in HbA1c at 12 months in new onset T1D.

Systematic reviews of continuous glucose monitoring (CGM) for type 1 diabetes (T1D) show that use of CGM leads to improvements in glycaemic metrics, with increased time in range (TIR), healthier HbA1c and reduced frequency of hypoglycaemia.[1–3] Further, early use of CGM has been associated with improved glycaemic outcomes.[4] Despite the body of evidence showing the beneficial effect of CGM, it is not publicly funded in Aotearoa New Zealand. Individuals with T1D can choose to use publicly funded self-monitoring blood glucose (SMBG) or self-funded CGM, introducing a financial barrier, especially for those of lower socio-economic status (SES).

Inequities in glycaemic outcomes based on ethnicity and SES for children living with T1D in Aotearoa New Zealand have recently been shown by Burnside et al.[5] This cross-sectional study also found inequities present in CGM use, where those of Māori ethnicity and lower SES had decreased access to CGM technology. Further, CGM use ameliorated differences in HbA1c predicted by ethnicity, independent of SES. Differences in HbA1c have long-term health impacts and addressing these inequities is a priority in line with Te Whatu Ora – Health New Zealand and the former Te Aka Whai Ora – Māori Health Authority's priorities.[6,7]

Long-term HbA1c trajectories are established within the first few years of being diagnosed with T1D and are influenced by the use of CGM.[4] Therefore, there appears to be a window of opportunity in the immediate period after diagnosis to influence the emergence of disparate glycaemic outcomes based on ethnicity and SES. While there are many potential modifiable risk factors beyond ethnicity and SES, CGM may have a positive influence, especially considering the aforementioned cross-sectional data. Therefore, the aim of this study is to investigate if inequities in paediatric T1D outcomes exist 12 months after diagnosis, and to investigate the impact of CGM on any observed disparities.

Method

In this retrospective cohort study, de-identified data were collected via the KIWIDIAB network. KIWIDIAB is an Aotearoa New Zealand data network that collects clinical and demographic data from children and adults with T1D across

Aotearoa New Zealand (Ethics Committee reference number HD18/098). For this study, data from children diagnosed with T1D under the age of 15 years between 1 October 2020 and 1 October 2021 were included. The inclusion criteria were: a diagnosis of T1D as per the American Diabetes Association Classification on 1 October 2021 between 1 October 2020 and 1 October 2021, age under 15 years on 1 October 2021 and managed by a secondary care paediatric diabetes centre in Aotearoa New Zealand (accounting for >95% cases).[8] Ethnicity was prioritised according to the NZ Ethnicity Data Protocols.[9] Individuals were able to identify with up to six ethnicities, which are ordered and grouped as: Māori, Pacific peoples, Asian, European/Other (including NZ European), as per previous publications.[5]

In addition to demographic and clinical data, socio-economic status (SES) was estimated using the New Zealand Index of Deprivation 2018 (NZ Dep2018). NZDep measures area-based relative socio-economic deprivation based off nine questions in the New Zealand Census of Population and Dwellings. It measures deprivation of small geographical land areas called meshblocks and orders these into deciles of deprivation, each containing about 10% of the population.[10] Address of domicile was converted to meshblock codes. Meshblock codes were matched with the NZDep2018 to estimate deprivation in quintiles; quintile 1 contains the least deprived 20% of the Aotearoa New Zealand population and quintile 5 contains the most deprived 20%.

The HbA1c result closest to 1 year post-diagnosis was collected as the health outcome measure. Most data returned an HbA1c result within 1 month of the year post diagnosis date. However, due to the COVID-19 lockdowns some results were delayed. Notably, results from four individuals in Northland District Health Board were delayed on average by approximately 5 months. CGM use was defined by using any commercially available CGM (including intermittently scanned) at the time of the last HbA1c.

Statistical methods

Demographic characteristics (age in 5-year categories, gender, ethnicity and NZDep) of the study sample were summarised as counts and percentages. CGM use was summarised as counts and percentages according to children's characteristics, and HbA1c as means and standard deviation by children's characteristics and use of CGM. Associations between CGM use and children's demographic characteristics were tested using univariable and multivariable generalised linear regression models followed by asymptotic Chi-squared tests. Group comparisons versus the reference category were calculated as risk ratios (RR) with 95% confidence intervals (CI), using Poisson regression models with robust "sandwich" standard errors.

Associations between children's glycaemic control and their demographic characteristics or use of CGM was investigated by using linear regression models to estimate between-group differences in mean HbA1c with 95% CI. Sub-group analysis, by use of CGM, was used to explore the potential importance of access to CGM in influencing observed differences by ethnicity. Analysis was conducted using R Statistical Software (v4·1·1; R Core Team 2021), with the package *emmeans* (v1·7·0; Lenth 2021) used to estimate marginal means and group contrasts.

Results

Demographics

Data were analysed from 206 children under 15 years old with T1D, which was collected through KIWIDIAB paediatric centres, and covered all regions in Aotearoa New Zealand. Ethnicity and demographic data and use of CGM at 12 months are presented in **Table 1**. Over one in four (27.7%) children newly diagnosed with T1D were of non-European ethnicity, approximately half of whom (14.6% of total) were Māori. The mean age at diagnosis was 8.8 years old; 47.1% were between ages 10 to 14, 37.9% were between 5 to 9 and 15% were under 5 years old.

CGM use

Overall, 69.9% of all individuals were using CGM. In Māori children, the mean use was 56.7% compared to 77.2% for Europeans in our study. And, in our study European children were 1.23 (0.85 to 1.79, p=0.42) times as likely to be using CGM compared to Māori when adjusted for SES, age and gender. Those with the lowest SES compared to the highest were 0.66 (0.44 to 1.00, p=0.053) times as likely to be using CGM when adjusted for ethnicity, age and gender (**Table 1**).

HbA1c and deprivation

The overall mean (SD) HbA1c at 12 months was 62.4 (14.2) mmol/mol. A higher HbA1c was associated with a lower SES, with those in the most deprived quintile (quintile 5) recording a mean HbA1c

Table 1: CGM use at 12 months according to age, gender, ethnicity and deprivation score.

	Children,	Using CGM, n (row %)		Unadjusted		Adjusted[1]	
	n (col %)	No	Yes	Risk ratio[2] (95% CI)	p	Risk ratio (95% CI)	p
Age							
0 to 4	31 (15.0%)	2 (6.5%)	29 (93.5%)	*Ref*		*Ref*	
5 to 9	78 (37.9%)	24 (30.8%)	54 (69.2%)	0.74, (0.61, 0.90)	<0.001	0.81 (0.66, 0.99)	0.008
10 to 14	97 (47.1%)	36 (37.1%)	61 (62.9%)	0.67, (0.55, 0.82)		0.73 (0.60, 0.90)	
Gender							
Female	96 (46.6%)	25 (26.0%)	71 (74.0%)	*Ref*	0.236	*Ref*	0.185
Male	110 (53.4%)	37 (33.6%)	73 (66.4%)	0.90, (0.75, 1.07)		0.90 (0.76, 1.05)	
Ethnicity[3]							
Māori	30 (14.6%)	13 (43.3%)	17 (56.7%)	*Ref*		*Ref*	
Pacific peoples	15 (7.3%)	13 (86.7%)	2 (13.3%)	0.24, (0.05, 1.17)	0.018	0.26 (0.05, 1.23)	0.049
Asian	12 (5.8%)	2 (16.7%)	10 (83.3%)	1.47, (0.90, 2.39)		1.44 (0.88, 2.34)	
European	149 (72.3%)	34 (22.8%)	115 (77.2%)	1.36, (0.92, 2.02)		1.23 (0.85, 1.79)	
NZDep							
1–2	56 (27.2%)	8 (14.3%)	48 (85.7%)	*Ref*		*Ref*	
3–4	33 (16.0%)	5 (15.2%)	28 (84.8%)	0.99, (0.79, 1.24)		0.96 (0.76, 1.22)	
5–6	41 (19.9%)	11 (26.8%)	30 (73.2%)	0.85, (0.65, 1.12)	0.002	0.88 (0.69, 1.13)	0.043
7–8	42 (20.4%)	20 (47.6%)	22 (52.4%)	0.61, (0.42, 0.90)		0.67 (0.46, 0.97)	
9–10	34 (16.5%)	18 (52.9%)	16 (47.1%)	0.55, (0.34, 0.88)		0.66 (0.44, 1.00)	
Total	206 (100%)	62 (30.1%)	144 (69.9%)				

Continuous glucose monitoring = CGM; confidence interval = CI; reference category = Ref; New Zealand Index of Deprivation = NZDep (1 = least deprived, 10 = most deprived).
[1]Estimates calculated from single multivariable model including age, gender, ethnicity and NZDep.
[2]Risk ratio interpreted as increased likelihood of CGM use versus the reference category where 1 equals no difference.
[3]Individuals identifying with multiple ethnicities are prioritised to a single ethnicity in the order listed.

that was 11 (5.7 to 17, p<0.001) mmol/mol higher compared with the least deprived regions (quintile 1), when adjusted for age, gender, ethnicity and CGM use (Table 2).

HbA1c, ethnicity and CGM use

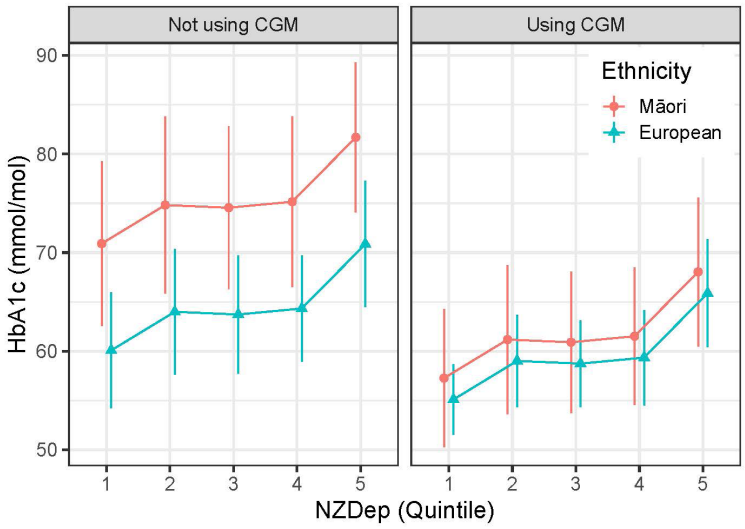
The mean HbA1c in Māori children 1 year after diagnosis was 9.4 (4.0 to 15, p<0.001) mmol/mol higher than in European children (69.6 mmol/mol vs 60.2 mmol/mol respectively). Previous research had indicated there was an interaction effect between ethnicity and CGM use on mean HbA1c.[5] Due to small numbers of children of Asian or Pacific ethnicity, we explored this for children of Māori and European ethnicity only. **Figure 1** and **Table 3** demonstrate the interaction

Table 2: Mean HbA1c at 12 months according to age, ethnicity deprivation score and use of CGM.

	HbA1c, mmol/mol	Unadjusted		Adjusted[1]	
	mean (SD)	Mean diff.[2] (95% CI)	p	Mean diff. (95% CI)	p
Age			0.082		0.4
0 to 4	57.1 (9.5)	*Ref*		*Ref*	
5 to 9	63.3 (14.3)	6.2, (0.29, 12)		3, (-2.5, 8.6)	
10 to 14	63.3 (15.1)	6.2, (0.44, 12)		3.6, (-1.8, 9.0)	
Gender			0.072		0.042
Female	60.4 (15.0)	*Ref*		*Ref*	
Male	64.0 (13.4)	3.6, (-0.32, 7.5)		3.8, (0.13, 7.5)	
Ethnicity[3]			<0.001		0.2
Māori	69.6 (16.9)	*Ref*		*Ref*	
Pacific peoples	71.1 (11.7)	1.5, (-7.0, 10)		-2.7, (-11, 5.5)	
Asian	59.8 (10.6)	-9.9, (-19, -0.66)		-8.1, (-17, 0.81)	
European	60.2 (13.4)	-9.4, (-15, -4.0)		-5.5, (-11, -0.22)	
NZDep			<0.001		0.008
1–2	57.1 (9.8)	*Ref*		*Ref*	
3–4	60.7 (11.5)	3.6, (-2.3, 9.4)		4.2, (-1.4, 9.9)	
5–6	61.7 (12.0)	4.6, (-0.86, 10)		3.6, (-1.7, 8.9)	
7–8	63.4 (17.1)	6.3, (0.85, 12)		3.5, (-1.9, 9.0)	
9–10	72.0 (16.7)	15, (9.1, 21)		11, (5.4, 17)	
Uses CGM			<0.001		0.006
No	69.6 (16.0)	*Ref*		*Ref*	
Yes	59.2 (12.2)	-10, (-14, -6.4)		-6.2, (-11, -1.8)	
Total	62.4 (14.2)				

Continuous glucose monitoring = CGM; confidence interval = CI; reference category = Ref; New Zealand Index of Deprivation = NZDep (1 = least deprived, 10 = most deprived).
[1]Estimates calculated from single multivariable model including age, gender, ethnicity, NZDep and use of CGM.
[2]Mean difference, interpreted as difference in mean HbA1c versus the reference category where 0 equals no difference.
[3]Individuals identifying with multiple ethnicities are prioritised to a single ethnicity in the order listed.

Figure 1: Estimated mean HbA1c at 12 months across deprivation quintiles split by CGM use and ethnicity.



Continuous glucose monitoring = CGM; New Zealand Index of Deprivation = NZDep (1 = least deprived, 5 = most deprived).
Individuals identifying with multiple ethnicities are prioritised to a single ethnicity in the order listed.
Adjusted for: age and gender. Shown with 95% confidence intervals.

Table 3: Difference in mean HbA1c between children of Māori or European ethnicity, stratified by CGM use.

	HbA1c, mmol/mol	**HbA1c difference (comparator group—reference group)**	
Glucose modality and ethnicity	**Mean (SD)**	**Unadjusted difference[1] (95% CI)**	**Adjusted difference[2] (95% CI)**
Not using CGM			
Māori (n=13)	79.5 (19.7)	Ref	Ref
European (n=34)	65.9 (15.2)	-13.5 (-21.9, -5.1)	-10.8 (-19.4, -2.3)
Using CGM			
Māori (n=17)	62.1 (9.3)	Ref	Ref
European (n=115)	58.5 (12.4)	-3.6 (-10.3, 3.1)	-2.2 (-8.9, 4.5)

Continuous glucose monitoring = CGM; confidence interval = CI; Reference category = Ref.
[1]Unadjusted differences calculated from single multivariable model including ethnicity and use of CGM, with an interaction between ethnicity and use of CGM.
[2]Adjusted differences calculated from single multivariable model including age, gender, ethnicity, NZDep and use of CGM, with an interaction between ethnicity and use of CGM.

of CGM with HbA1c and ethnicity. For children not using CGM, Māori had a HbA1c 10.8 (2.3 to 19.4, p=0.013) mmol/mol higher than European children after adjustment for SES, gender and age. For children using CGM, there was no evidence of a difference in HbA1c between children of Māori versus European ethnicity (mean difference = 2.2, -4.5 to 8.9, p=0.53).

Discussion

This study demonstrates that inequities in HbA1c are present at 12 months from diagnosis of T1D in children under 15 years old in Aotearoa New Zealand according to both SES and ethnicity, and disparate glycaemic outcomes based on ethnicity may be reduced by CGM use. Fewer Māori were using CGM, partially but not entirely explained by SES, consistent with a national paediatric cross-sectional study.[5] Māori children were found to have a mean HbA1c higher than European children after 1 year, after accounting for SES. These data confirm that social determinants of health outcomes are present very early or by 12 months in a person's journey with T1D, and align with cross-sectional Aotearoa New Zealand paediatric T1D data[5] and international literature for both T1D and T2D.[11]

PHARMAC (the national pharmaceutical and device funding agency in Aotearoa New Zealand) recently announced that CGM will be funded for all people with T1D in Aotearoa New Zealand.[12] In order to fulfil the equitable health mandate according to the principles of Te Tiriti o Waitangi, it is essential that those with the most need are prioritised in accessing the technology.[13] Other health systems, such as in Australia, have demonstrated population health benefits from funded CGM health policy.[14]

While access to technology is likely to be a critical element to reducing disparity, other factors need addressing including provider bias, institutionalised racism, models of care and provisions of well-resourced, highly skilled healthcare professionals. Geographic variation in patient to healthcare professional (HCP) ratios have been demonstrated in Aotearoa New Zealand.[15] HCP ratios fall short of international standards,[16,17] and have not substantially changed over a decade, despite increasing complexity of management with respect to contemporary diabetes technology. Therefore, while funding CGM is critical to improving diabetes equity, addressing SES and providing a well-resourced multi-disciplinary team are also important.

A strength of this study was the data provided by KIWIDIAB diabetes network, which is estimated to capture >95% of all children with T1D in Aotearoa New Zealand.[8] Accordingly, this study likely covered a very high proportion of the population, reducing sampling bias and increasing representativeness. However, the study power and precision of estimates were limited by the relatively small number of children diagnosed with T1D each year in Aotearoa New Zealand. In particular, low numbers of Pacific and Asian children prevented detailed analysis in these sub-groups. The cross-sectional audit found Pacific children had a HbA1c even higher than Māori, so this population is at high risk.[5] Socio-economic status was estimated using NZDep2018, and as this is an area-based measure of deprivation rather than individual-specific, it may introduce potential confounding, but is well validated.[10] HbA1c results were not exactly 1-year post diagnosis due to COVID-19 lockdowns, so this may have influenced some HbA1c results as patients come out of the partial remission phase. Insulin treatment modality was not controlled for within the model; however, at 12 months post diagnosis very few patients were using insulin pump therapy (assumed to be due to PHARMAC criteria). We were also unable to collect data on the percentage of CGM use, or the relative impact of either intermittently scanned or real time CGM. Further, we did not collect data on the amount of clinical contact any users had with respect to guidance while using CGM and titrating insulin dosage.

This study has provided further evidence of inequities present in paediatric T1D technology use and HbA1c in Aotearoa New Zealand. Furthermore, it has demonstrated that inequities are formed early, within the first year of diagnosis. Findings of this study suggests funding CGM would decrease HbA1c and improve health outcomes for all New Zealanders, and further ameliorate the ethnic inequities that are starkly present. With the recent PHARMAC announcement for fully funded CGM, these data provide an essential baseline perspective.

COMPETING INTERESTS
Nil.

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Examining the approaches used to assess decision-making capacity in healthcare practice

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ABSTRACT

AIM: To examine the approaches that are being used in New Zealand when conducting decision-making capacity (DMC) assessments among the healthcare professionals that commonly conduct DMC assessments and those that are involved in, but do not conduct, the assessments.

METHOD: An online quantitative survey was conducted, lasting 10 minutes, including a mix of closed- and open-ended questions. The survey garnered responses from a total of n=78 participants.

RESULTS: Bedside cognitive tests were found to be the most commonly reported tool used to assess DMC among those conducting and those contributing to DMC assessments. Nearly a third (31.9%) of participants conducting DMC assessments used a structured clinical interview as one of their most common approaches while 27.5% of this same group reported not being aware of this approach. It was reported by both those conducting and those contributing to DMC assessments that the current standards lack quality and consistency, with partial capacity being poorly understood and identified, and supported decision making often being overlooked for substitute decision making.

CONCLUSIONS: Current approaches to DMC assessment lack standardisation and consistency, with assessment approaches being widely varied. This article serves as a call for the development of and adherence to nationally recognised standards for DMC assessments.

Decision-making capacity (DMC) denotes the capability to make a decision at a specific time. Healthcare professionals are responsible for conducting DMC assessments, but the outcome can have indefinite legal consequences for an individual.[1] Informal DMC assessment occurs frequently by healthcare practitioners as part of the legal and ethical responsibility to obtain informed consent for treatment.[2] Formal DMC assessment occurs when an individual's DMC has been called into question and an assessment is required for legal purposes in examples, such as under the *Protection of Personal and Property Rights Act (PPPR) 1998* or capacity to make a will.[1] A formal DMC assessment should assess an individual's ability to understand the information given, retain the information for a required time, use and weigh the information and communicate a decision.[1] Many DMC assessments are straightforward, but others can be complex and require extensive ethical, reflective and adaptive approaches.[3] This may be due to several different factors—for example, subtle or fluctuating cognitive impairment such as dementia,[4] mental illness and involvement of mental health acts,[5] aphasia,[6] persons with disabilities[7] or differing professional opinions.[8]

Recent Australasian research has highlighted concerns with how DMC assessments are being conducted, and provided evidence of considerable variation.[9–13] For example, a survey of Australian healthcare practitioners found that 31% of DMC assessors used a capacity assessment tool, 52% used a screening tool and 77% used professional judgement[11] despite it being argued that screening tools are not suitable for DMC assessment and should not be used.[14] Documentation of DMC assessments is also varied. A retrospective case note review in Australia found that 33% of patients referred for guardianship applications had no documented evidence of a completed DMC assessment.[10]

While doctors appear to be conducting most DMC assessments in New Zealand,[12,15] it is a task also performed by nurse practitioners and clinical psychologists/neuropsychologists.[16] Nurse practitioners have a wide range of assessments within their scope[17] while clinical psychologists/neuropsychologists are trained in the use of various in-depth assessments.[18] Research in Australia has found that healthcare professionals

of multi-disciplines are often involved,[6,19] while in other jurisdictions such as England and Wales, social workers and speech-language therapists are responsible for conducting DMC assessments under the *Mental Capacity Act 2005* (England and Wales).[20]

Although it is known that the current approaches to assessing DMC vary, to the best of our knowledge there is no research in New Zealand that has captured exactly *how* these assessments are being conducted, *who* they are being conducted by and *which* tools and approaches are being used. The aim of the study was to understand the approaches that are being used in DMC assessments in New Zealand by those conducting them and those who identify as being involved in or contributing to them. It was anticipated that this could be used to indicate what, if any, practice or training changes are needed. At the time of this study the *End of Life Choice Act 2019* was a relatively new legislation in New Zealand. Given that this *Act* is the only circumstance in which DMC is not presumed and an assessment must be completed, we included a question in our survey to explore how the *Act* has impacted DMC assessments in this new clinical situation.

Methods

Survey design

The first author designed the survey after completing a detailed review of Australasian literature on DMC assessments. The co-authors provided feedback on the content and flow. The survey was administered through Qualtrics[XM] (a web-based survey tool). Table 1 provides the six survey questions about current approaches used to assess DMC. The questions listed here are a selection from a larger project (see https://nzmj.org.nz/journal/vol-136-no-1593/exploring-training-involvement-and-confidence-a-study-of-healthcare-professionals-in-decision-making-capacity-assessments for full survey questions and analysis).

Following ethics approval (reference number UAHPEC: 23678), data were collected between January and April 2022. All responses were anonymous and no identifiable information was gathered in the questionnaire.

Participants

Participants were recruited through various professional colleges (namely General Practitioners [GP], Psychiatry and Clinical Psychology) and associations (representing nurse practitioners, speech-language therapists, occupational therapists, social workers and psychologists). Relevant community organisations and interest groups were also contacted. All participants needed to have met the eligibility criteria of being a healthcare professional with some involvement in DMC assessments, having read the participant information sheet and agreeing to participate.

Data analysis

Data collected on Qualtrics[XM] were downloaded to Microsoft Excel (2022). Participants were classified into two groups. The first group were those healthcare professionals who commonly conduct DMC assessments (namely, medical practitioners, nurse practitioners and clinical psychologists/neuropsychologists); referred to as the "conducting" group. All other healthcare professionals who identified as being involved in DMC assessments were referred to as the "contributing to" group (largely consisting of social workers, speech-language therapists, occupational therapists and nurses). Descriptive analysis was used to compare the responses provided by both groups. The survey included several open-ended questions, and an inductive qualitative content analysis (informed by Elo and Kyngäs[21]) was undertaken to analyse these responses.

Results

A total of 171 participants opened the survey and met eligibility criteria (via self-identifying). Ninety-three (54.4%) participants did not complete the survey, with the majority (n=53, 57.0%) dropping out after the first two questions. This left 78 (45.6%) fully completed responses. The results analysed and presented here were for those 78 completed responses. The demographics for the "conducting" and "contributing to" groups are shown in Table 2.

Awareness and use of tools or approaches

When answering the open text Question 1 (requesting a list of tools or approaches they are aware of or use), participants provided a wide variety of responses (shown in Table 3). More than one approach was spontaneously mentioned by 55 (70.5%) participants. Bedside cognitive tests were more commonly reported by those in the "contributing to" group (41.9%, compared to 12.8%

Table 1: Survey questions on approaches in DMC assessments.

Question	Response options
1. Please list any tools or approaches you either use, or are aware of, for conducting decision-making capacity assessments.	Open-ended response
2. Which of the following best describes your knowledge and use of each of the following tools/methods as part of conducting decision-making capacity assessments? a. Aid to Capacity Evaluation b. MacCAT-T (MacArthur Competence Assessment Tool for Treatment) c. Neuropsychological tests (e.g., WAIS IV, WMS IV) d. Bedside cognitive tests (e.g., Montreal Cognitive Assessment, Addenbrooke's Cognitive Examination, Mini-Addenbrooke's Cognitive Examination, Mini-Mental State Examination) e. Vignette method—please specify f. Structured clinical interview—please specify g. Other—please specify	1. Most common approach I use 2. Use sometimes 3. Aware of this but do not use 4. Not aware of this
3. Which of the following best describes your knowledge and use of the Toolkit for Assessing Capacity (part of the book *Assessment of Mental Capacity* by Douglass, Young and McMillan)?	A. Use this toolkit as my most common approach to assess capacity B. Use this toolkit sometimes to assess capacity C. Aware of this toolkit but do not use it D. Not aware of this toolkit
4. Do you have any other comments to make about the current processes or approaches in place for the assessment of a patient's decision-making capacity?	Open-ended response
5. Given the recent approval of the *End of Life Choice Act (2019)*, do you think any changes are required to the assessment of a patient's decision-making capacity?	Yes No Unsure
6. What changes do you think are required?*	Open-ended response

WAIS IV = Wechsler Adult Intelligence Scale 4th ed.; WMS IV = Wechsler Memory Scale 4th ed.
*Asked only to those who selected yes at Q5.

in the "conducting" group). They also named more *other structured tools* such as the Cognistat Cognitive assessment and the Allen's Cognitive Level Screen. Those in the "conducting" group mentioned more of the available guidelines to assist in the assessment of DMC, namely the *Toolkit for Assessing Capacity*[1] along with "*Peter Darzin's 6 step capacity assessment process*"[22] and "*various teaching mnemonics e.g., Play Soccur*", an assessment procedure detailed by Young[23] covering presenting complaint, situation, options, consequences, consistency, undue influence, reasoning and executive ability.

Table 4 summarises responses to question 2; the prompted use of each tool or approach. Bedside cognitive tests were reported as the most

Table 2: Characteristics of participants who completed the survey.

Characteristics	Response	Role in decision-making capacity assessments	
		Conducting N=47 n (%)	Contributing to N=31 n (%)
Gender	Male	11 (23.4)	2 (6.5)
	Female	36 (76.6)	29 (93.5)
Age	Under 30 years	1 (2.1)	6 (19.4)
	30–44 years	13 (27.7)	8 (25.8)
	45–55 years	18 (38.3)	5 (16.1)
	Over 55 years	15 (31.9)	12 (38.7)
Ethnicity	European	36 (76.6)	30 (96.8)
	Māori	3 (6.4)	4 (12.9)
	Asian	3 (6.4)	1 (3.2)
	Other	6 (12.8)	0 (0.0)
	Prefer not to say	1 (2.1)	0 (0.0)
Profession	Medical practitioner	25 (53.2)	0 (0.0)
	Nurse practitioner	10 (21.3)	0 (0.0)
	Clinical neuropsychologist	12 (25.5)	0 (0.0)
	Occupational therapist	0 (0.0)	11 (35.5)
	Social worker	0 (0.0)	12 (38.7)
	Speech-language therapist	0 (0.0)	4 (12.9)
	Other*	0 (0.0)	4 (12.9)
Years of professional experience	Fewer than 6 years	8 (17.0)	5 (16.1)
	6–10 years	8 (17.0)	5 (16.1)
	11–20 years	12 (25.5)	8 (25.8)
	Over 20 years	19 (40.4)	13 (41.9)
Work setting	Public hospital	25 (53.2)	21 (67.7)
	Private practice (group/solo)	11 (23.4)	1 (3.2)
	Other	11 (23.4)	9 (29.0)

*Other group included advocate/advocacy manager (n=2), pharmacist (n=1), nurse (n=1).

Table 3: Spontaneous mentions of tools or approaches used to assess DMC.

	Conducting N=47 n (%)	**Contributing to N=31 n (%)**
Structured tools		
Bedside cognitive tests (e.g., Montreal Cognitive Assessment, Mini-Mental State Examination, Mini-Addenbrooke's Cognitive Examination)	6 (12.8)	13 (41.9)
Neuropsychological/psychometric assessment	9 (19.1)	0 (0.0)
Aid to Capacity Evaluation	3 (6.4)	3 (9.7)
MacCAT-T (MacArthur Competence Assessment Tool for Treatment)	1 (2.1)	0 (0.0)
Other structured tools (specified)*	1 (2.1)	13 (41.9)
Specific mention of no structured tool	2 (4.3)	3 (9.7)
Guidelines		
Toolkit/Assessment of Mental Capacity Book	9 (19.1)	2 (6.5)
Other guidelines (specified)*	5 (10.6)	0 (0.0)
Assessment tools/guidelines (unspecified)	3 (6.4)	2 (6.5)
General approaches/considerations		
Family involvement/collateral information	13 (27.7)	8 (25.8)
Clinical interview/discussion with client	9 (19.1)	4 (12.9)
Assessment consideration (e.g., cultural factors, comm. support)	9 (19.1)	4 (12.9)
Local service guidelines/health pathways	11 (23.4)	2 (6.5)
Professional consultation/specialist referral	6 (12.8)	4 (12.9)
Legal documents (e.g., PPPR, affidavit)	7 (14.9)	1 (3.2)
Medical screen/test/considerations	6 (12.8)	4 (12.9)
Note review/history/information gathering/preparation	4 (8.5)	3 (9.7)
Own knowledge/experience/education	5 (10.6)	3 (9.7)
International guidelines (United Kingdom and Australia)	4 (8.5)	2 (6.5)
Online resources	4 (8.5)	0 (0.0)
Observation	3 (6.4)	3 (9.7)
Functional assessment	0 (0.0)	3 (9.7)
Other approaches*	8 (17.0)	4 (12.9)
Unaware of any	0 (0.0)	1 (3.2)

*Classified as other if fewer than three unique mentions.
PPPR = *Protection of Personal and Property Rights Act 1988*.

Table 4: Prompted frequency of approaches used.

	Aid to Capacity Evaluation		MacArthur Competence Assessment Tool for Treatment		Neuropsychological tests (e.g. WAIS IV, WMS IV)		Bedside cognitive tests*		Vignette method		Structured clinical interview		Other	
	Conducting n (%)	Contributing to n (%)	Conducting n (%)	Contributing to n (%)	Conducting n (%)	Contributing to n (%)	Conducting n (%)	Contributing to n (%)	Conducting n (%)	Contributing to n (%)	Conducting n (%)	Contributing to n (%)	Conducting n (%)	Contributing to n (%)
The most common approach I use (or others use)	3 (6.4)	3 (9.7)	0 (0.0)	0 (0.0)	11 (23.4)	3 (9.7)	18 (38.3)	15 (48.4)	5 (10.6)	0 (0.0)	15 (31.9)	7 (22.6)	9 (19.1)	5 (16.1)
Use this approach sometimes	5 (10.6)	2 (6.5)	2 (4.3)	0 (0.0)	5 (10.6)	4 (12.9)	14 (29.8)	7 (22.6)	3 (6.4)	1 (3.2)	6 (12.8)	4 (12.9)	2 (4.3)	0 (0.0)
Aware of this approach but do not use	8 (17.0)	5 (16.1)	13 (27.7)	3 (9.7)	16 (34.0)	10 (32.3)	11 (23.4)	6 (19.4)	7 (14.9)	3 (9.7)	10 (21.3)	7 (22.6)	4 (8.5)	0 (0.0)
Not aware of this approach	30 (63.8)	20 (64.5)	31 (66.0)	27 (87.1)	13 (27.7)	13 (41.9)	2 (4.3)	2 (6.5)	25 (53.2)	26 (83.9)	13 (27.7)	11 (35.5)	21 (44.7)	21 (67.7)
No answer	1 (2.1)	1 (3.2)	1 (2.1)	1 (3.2)	2 (4.3)	1 (3.2)	2 (4.3)	1 (3.2)	7 (14.9)	1 (3.2)	3 (6.4)	2 (6.5)	11 (23.4)	31 (16.1)

WAIS IV = Wechsler Adult Intelligence Scale 4th ed.; WMS IV = Wechsler Memory Scale 4th ed.
* e.g., Montreal Cognitive Assessment, Addenbrooke's Cognitive Examination, Mini-Addenbrooke's Cognitive Examination, Mini-Mental State Examination.

commonly used by both groups. Among the 18 (38.3%) participants in the "conducting" group who reported using bedside cognitive tests most often, six (33.3%) also selected at least one other tool/approach that they use *most often*, four (22.2%) did not select any others for using *most often* but selected at least one for *use sometimes,* and eight (44.4%) selected bedside cognitive test as the only tool/approach used. The MacArthur Competence Assessment Tool for Treatment (MacCAT-T),[24] which is arguably considered the gold standard for assessing DMC overseas,[15] is not being used as the most common approach by anyone surveyed, with only 13 (27.7%) of those in the "conducting" group aware of the tool but not using it. Nearly one-third (31.9%) of those in the "conducting" group are using a structured clinical interview as one of their most common approaches, while 13 (27.7%) participants in this group are not aware of the approach. Other approaches mentioned were "*United Kingdom structure for assessments*", "*form developed by our service*", "*unstructured clinical interview*" and "*supported needs assessments.*"

The Toolkit for Assessing Capacity[1] is a semi-structured guideline designed in New Zealand and adopts the functional test of mental capacity as in the *Mental Capacity Act 2005* (England and Wales).[20] It is designed to help multidisciplinary healthcare professionals involved in the assessment of DMC and is regarded as the legal and professional standard under the *Health and Disability Services Consumers' Code of Rights*. Given the significance of this locally developed tool, we asked participants about their awareness and use of it in a separate question. Just over half (51.1%) of those in the "conducting" group were aware of the toolkit with 11 (23.4%) using it as their most common approach. One fifth (21.3%) were aware of the toolkit but not using it. A similar level of awareness was also seen among those in the "contributing to" group with 13 (41.9%) stating they were aware of this approach.

Current processes and approaches

Question 3 elicited open-ended comments about the current processes and approaches in place for DMC assessments. Analysis of these comments highlighted four key concerns. The two most mentioned concerns were "quality issues" and "consistency/standardisation" with legal components and complexities of the concept of "partial capacity" also mentioned. Partial capacity refers to when an individual may be able to show evidence of some but not all elements of DMC, such as the ability to understand, retain and communicate but may struggle with weighing up options. DMC was commonly recognised as potentially having significant consequences on an individual's life, requiring a robust process that reflects these consequences. Comments on quality issues included concerns about the current workplace processes being *ad hoc* and DMC reports lacking detail: "*The court system should not allow people to be stripped of their decision-making rights based on an inadequate form that doctors fill in that does not involve any form of comprehensive capacity assessment, lacks detail and is carried out by a clinician who has not been trained in assessing capacity.*" One participant noted a practice of concern: "*I've had GPs write complete forms for, with the guardianship under the* Personal Properties and Rights Act. *But, they've done that without even seeing somebody, because they had a low MoCA, you know, six months ago.*" Time pressures were acknowledged by participants as a constraint on conducting comprehensive DMC assessments in the public system.

Consistency and standardisation were raised as issues in approaches to assessing DMC: "*The current system and processes are not comprehensive enough. There needs to be a standardised and effective decision-making capacity assessment which is rolled out and implemented nationally.*" This area of clinical practice was reported to be devoid of uniform guidelines to aid assessors in the process of assessing DMC: "*There needs to be proper guidelines and policies for how exactly we do this. It's very grey and to take someone's capacity away without proper guidelines in New Zealand is a concern.*"

Participants highlighted the complex nature of "partial capacity" and the interaction it has with the law. One participant said, "*It can feel like a 'yes they have capacity' or 'no they don't have capacity' rather than decision specific approaches*" and that "*often I would consider clients to have 'partial capacity' which is not helpful with PPPR.*" One participant went further to say that "*I would like to see our PPPR legislation change to allow that capacity assessment be decision-specific and to incorporate supported decision-making concepts.*" Several comments were made about the need to move towards supported decision making and align better with the United Nations Convention on the Rights of Persons with Disabilities.[25]

End of life

When asked about the impact of the *End of*

Life Choice Act (2019) in New Zealand, 19 (40.4%) participants in the "conducting" group felt that changes in the assessment of an individual's DMC are required. However, the same number responded that they were unsure if changes are needed, and the remaining nine (19.1%) participants felt that changes are not needed. The majority (54.8%) of participants in the "contributing to" group were unsure if changes are needed, with 13 (41.9%) stating that changes are needed and one person (3.2%) stating that changes are not needed.

For those who responded that changes *are* required, an open-ended question captured their suggestions. Comments in the "conducting" group mostly focussed on the need for a clear and consistent approach with a firm standard that is nationally recognised, followed by comments focussed on training needs and skill, e.g., "*Standard test—country wide used by formally trained clinicians*", "*Much better training and consistency in approach to assessment.*" Comments were also made about the need to recognise partial capacity and the lack of involvement of psychologists in the *Act*. Those in the "contributing to" group also mentioned that the *Act* potentially overlooks the role of other healthcare professionals and the need for clinician training.

Discussion

DMC assessments are important clinical tasks that can have significant medico-legal consequences. They should therefore be comprehensive, robust and reliable. This cross-sectional survey supports previous research findings that those conducting DMC assessments are using a variety of different approaches[9–11] and there is a desire for a move towards a more standardised approach.[12,13]

This is the first study in New Zealand to explore the approaches being used to assess DMC by both those conducting and those contributing to them. Spontaneous and prompted responses highlighted that DMC assessments can be *ad hoc* and conducted using a multitude of different tools following varied, often locally developed, guidelines. Bedside cognitive tests were reported to be used by many participants surveyed. For those who did not select any other tools/approaches it would suggest that some clinicians are continuing to rely on these limited tests as a measure of capacity.[13] The surveyed healthcare professionals contributing to DMC assessments show just as much variation in what they use, potentially highlighting the level of knowledge held by some of those assisting but not commonly conducting DMC assessments. Given recent evidence to suggest that those not conducting DMC assessments feel that they do not have enough involvement,[26] there may exist an opportunity to better utilise this knowledge.

This study found that within individual clinicians the approach to assessing DMC can change. It has been argued that, for decisions that are deemed to be more serious or when a patient is acting against what is perceived to be in their best interests, a more involved DMC assessment is completed.[27] Furthermore, for more complex presentations it has been suggested that a more thorough assessment is needed, including referrals to specialists.[28] However, the determination of what is a complex assessment is a grey area and relies on the subjectivity of the assessor to ascertain the level of seriousness and as such, the level of formality of the assessment, likely leading to increased variability. Most participants in this study were very experienced clinicians, many of whom raised the issue of consistency and quality within these assessments. It is therefore likely that the results of this study under-estimate the issue if one also considers the less experienced clinicians in the workforce. It may be that learnings can be taken from the interRAI[32] system that is currently operating in the older adults sector in New Zealand. The interRAI provides a nationally standardised (and internationally validated) assessment to determine the appropriate level of care for individuals and is accessible by all clinicians working in this sector.

Partial capacity is an area of clinical practice that is not currently well understood or accounted for in the PPPR *Act*, with patients often being determined to wholly lack capacity and substitute decision making being the common outcome. As stated in the Toolkit for Assessing Capacity,[1] DMC assessments should be decision-specific; however, assessment outcomes that state an individual wholly lacks capacity is arguably incorrect as in many instances they may lack DMC to make more complicated decisions about their care, but retain the DMC for everyday cares, e.g., the decision to shower. With DMC assessments often focussed on cognition, individuals with intellectual disabilities are more likely to be found to wholly lack capacity and have their decision-making rights taken away.[7] As a ratifying nation, New Zealand has a duty to adhere to the United Nations Convention on the Rights of Persons with Disabilities.[25] The Convention positions itself to put efforts, wherever possible, into

involving an individual in the decision making. A move towards more supported decision-making practices as opposed to substitute decision making is warranted and requested from healthcare professionals.

Assisted dying is now legal in New Zealand, so it is concerning that most participants in this survey stated that changes are needed to the very assessment that determines if people are capable of making this decision. There was a clear request for a more standardised process that is uniform across the country and, supporting previous research among New Zealand-based psychiatrists,[29] and a recent viewpoint,[30] there was desire for increased knowledge and training for those conducting DMC assessment within this space.

Recommendations

DMC assessments need to be held to a clinical and legal nationally recognised standard with all healthcare professionals having access to formal training. It is suggested that a degree of flexibility will always be required given the inherent complexity of DMC and individual nuanced presentations. However, for straightforward cases patients should be receiving standardised assessments no matter who their clinician is, and for more complex cases there should always be the same starting point to limit the inherent variability. A detailed literature review proposed the Capacity Assessment Model of Practice.[28] The model outlines the process, considerations and knowledge necessary for a well-conducted DMC assessment, of which it is recommended to be considered for development of a standardised guideline. It is hoped that the current review of adult DMC law being carried out by the Law Commission[31] provides recommendations of a similar nature to those suggested in this study.

Strengths and limitations

This study is unique in its provision of detailed descriptions of how those involved in DMC assessments in New Zealand are assessing their patients. Combining qualitative and quantitative responses allowed for the reporting of clear data while adding depth and meaning to the responses. Open-ended questions have provided a clear direction for change. The small sample in this survey is the main limitation, limiting the analysis of assessment differences across individual professions. Demographics were not collected for those that did not complete the survey, and with a relatively high dropout rate we are unable to analyse the differences between those who completed the survey and those who did not. As we do not know the exact number of people who received the survey, we are unable to calculate the response rate and know if our results are representative of the healthcare workforce. It is likely that the participants who responded to the survey are those already engaged in this topic and therefore there is a sampling bias. Those who said *no* or *unsure* to changes being needed due to the *End of Life Choice Act (2019)* were not asked a follow-up question, thereby limiting our ability to analyse those responses. In addition, the spontaneous collection of approaches generated responses such as “a form developed by our service” and the survey did not allow for follow-up or clarification of responses to expand on what this was.

Future research

Change is required with a focus on providing clarity and detail on the current approaches and the changes required to ensure this area of clinical practice improves. As this is the first study in New Zealand to include those not currently recognised as conducting DMC assessments, more research is needed among this group. Research is also needed to ensure that changes made to the approach of DMC assessments are safe and culturally responsive to Māori and non-European ethnic groups. A co-design approach with key stakeholders could be considered when developing future DMC training courses to maximise end-user uptake of the resources.

Conclusion

Individual nuances within DMC mean that a flexible and adaptive response is likely to always be needed to some degree. However, this study provided evidence to show that the current approach to DMC assessment is widely varied, devoid of standards and has very little consistency. There is a call for a nationally recognised standard along with accredited training courses for how to approach and conduct these assessments.

COMPETING INTERESTS
Nil.

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Written information about retinopathy of prematurity in Aotearoa New Zealand: identification, review and opportunities for improvement

Holly White, Lisa Kremer, Liza Edmonds, Amber Young

ABSTRACT

AIMS: The aims of this research include adapting a patient information tool for whānau (extended family) Māori needs, identifying and reviewing written information provided for the retinopathy of prematurity eye examination (ROPEE) and identifying improvements to ROPEE written information.

METHODS: ROPEE patient information (printed leaflets, website, app) was obtained from all tertiary neonatal intensive care units in Aotearoa New Zealand (Aotearoa). Information was reviewed using an adapted "20 good-design principles" guide and given a star rating and Flesch–Kincaid readability score to identify acceptability and usability for patients.

RESULTS: Seven ROPEE information materials were reviewed and varied in alignment with the adapted good-design principles tool. Based on the adapted good-design principles, opportunities were identified in many aspects of the written information for improvement, including words and language, tone and meaning, content and design. The Flesch–Kincaid grade level reading scores ranged from 12–22 years reading age. Written information also did not use te reo Māori (Aotearoa Indigenous language) or extensively use Māori imagery.

CONCLUSION: Opportunities exist to improve ROPEE whānau information, including making content more readable, understandable and visually appealing. Optimising the clinical information on ROPEE nationally for Aotearoa will support whānau decision making, and aligning written information with Māori (Indigenous peoples of Aotearoa) is a priority.

Admission to the neonatal intensive care unit (NICU) is a stressful and often unplanned time for whānau (extended family).[1] Effective communication between healthcare workers and whānau reduces stress.[2,3] Other crucial factors for whānau wellbeing within the NICU include whānau involvement in healthcare, effective health education, emotional support and assurance.[4] Challenges in communication, such as lack of information, responsiveness, respect and consideration of culture can contribute to whānau dissatisfaction.[5] Additionally, low health literacy can have a detrimental impact on health and is associated with increased hospitalisation and healthcare costs, and reduced health outcomes.[6–8] The intensive care environment has unique challenges for staff-to-whānau communication given its highly emotional and technical environment.[9] Whānau of preterm infants receive a magnitude of information, much of which may require high levels of health literacy, and face challenges in decision making.[1] To support health literacy, understanding and information recall, it is beneficial to provide written information in addition to verbal information.[10] Written information has been found to be useful for conveying information and can assist whānau with decision making in the NICU.[7,10] Tools for assessment and evaluation of the quality of written information has been developed, including elements such language that can be understood, health literacy and the layout of information to optimise its impact to convey information.[11]

Written information is used to guide whānau in the NICU for different procedures including retinopathy of prematurity eye examinations (ROPEE). In Aotearoa New Zealand (Aotearoa) infants born <31 weeks gestational age and/or less than 1,250g birthweight are offered ROPEE. During this process, whānau are to be given verbal and written information (print or digital) about ROPEE as part of clinical care and to obtain

consent. Preterm infants who meet the eligibility criteria are screened for retinopathy of prematurity (ROP) to optimise outcomes with timely diagnosis and treatment preventing loss of visual acuity and permanent blindness.[12] Blindness in children is associated with increased hospitalisation, mortality, delayed development and poorer socio-economic status than children who do not have vision impairment, highlighting the importance of ROPEE.[13] Currently in Aotearoa, each NICU has developed their own ROPEE whānau information in varying forms (printed leaflet, website, app). Good design principles exist for written information[11] for whānau and the extent to which these apply to ROPEE information is yet to be explored.

The Australian and New Zealand Neonatal Network (ANZNN) data from 2021 demonstrated that 20.2% of eligible preterm infants did not have a ROPEE performed.[14] Eligibility criteria differ between the two countries, where Aotearoa New Zealand infants born fewer than 30 weeks gestational age and/or 1,250g birthweight are eligible, and Australian infants born fewer than 32 weeks gestational age and/or 1,500g birthweight are eligible. It is unclear currently as to why this significant number of infants, in line with each country's eligibility criteria, had missed opportunities for ROPEE. Supporting whānau consent and engagement in ROPEE through communication aids, such as written material, is important to ensure whānau are fully informed of eligibility for these tests, and this will have an impact on health outcomes. These opportunities are especially important for whānau who might not experience systemic privilege in outcomes, such as Māori who have a higher risk of extremely and very preterm birth and have a significantly higher relative risk of early neonatal death or post-neonatal death.[15] Māori infants account for 28% of preterm infants and an associated higher risk for ROP due to higher preterm birth rates.[15] Previous research has demonstrated that cultural, social and health inequities disproportionally affect Māori.[16,17] Te Tiriti o Waitangi (the Treaty of Waitangi), is an Aotearoa foundational document that holds the health system accountable to ensure whānau Māori experience equitable culturally safe health outcomes.[16,18] Given the higher rates of prematurity and health inequities experienced by whānau Māori, written NICU resources need to be culturally appropriate and optimise consent and engagement to provide whānau Māori the autonomy required for informed decision making around ROPEE. Additionally, the role of whānau within the NICU for reducing both whānau and pēpi (baby) stress has been demonstrated with Family Integrated Care (FiCare) approaches.[19,20]

The aims of this research are to identify and review written information whānau are provided for the ROPEE using the adapted good-design principle tool,[11] and to identify potential opportunities to improve the ROPEE written information within an Aotearoa context.

Methods

In Aotearoa, there are six tertiary (level 3) NICUs, and each were contacted between January and March 2023 and requested to provide their ROPEE written information to review. Each neonatal unit has between 16 and 41 beds from 23 weeks gestational age onwards. Additional ROPEE written information available online via a website or an app was also included in this review.

The "20 good-design principles" to evaluate medicine information by Young et al. were reviewed and modified for whānau of preterm infants to include two new principles (te reo Māori, Māori imagery) and five existing criteria for ROPEE clinical information.[11] These principles and criteria were added to consider Māori cultural concepts and information specific to the ROP condition. The new principles included reviews for inclusion of Māori imagery; use of te reo Māori (Māori language) and "ROPEE clinical information". The grading for te reo Māori was rated as absent or present.

Five criteria for "ROPEE clinical information" were identified based on clinical expertise and evidence-based medicine, including information provided on: what is ROP; why ROPEE are important; the procedure; what parents can do during the examination; and care after the examination. Assessing what information whānau receive for the entirety of the ROPEE was included to evaluate the education whānau receive about parental presence and involvement. Each source of information was reviewed by an experienced neonatologist ranking the information based on these criteria.

Information from the ROPEE material was reviewed against the adapted good-design principles and tabulated for comparison. Each resource was given a star rating, developed and based in accordance with the adapted good-design principles, by one investigator, which was corroborated by two researchers to support an assessment of how well the good-design principles

were met. The star rating was two stars for "consistent", one star for "somewhat consistent", and no stars for "not consistent". An assessment of ease of reading was established via the Flesch–Kincaid grade level, and Flesch–Kincaid reading ease score and average sentence length were obtained by running text from the written information through an online program.[20] The reading age of an 11-year-old was considered reasonable from a review of five regulatory agencies' recommendations for written medicine information.[11] For those containing Māori imagery, clarification was sought from the NICU if the whakapapa (history) of the images or meanings were not apparent on review.

Results

Written information from six hospitals was included within the analysis, with a total of seven information materials reviewed. Of these, five were printed and given in-person or via email to members of the research team. One hospital provided two written information materials; one was available on a website, and one was a free downloadable application. Each was analysed for the characteristics described in the Methods section and summarised in Table 1, using star ratings to identify consistency with principles.

The ROPEE written information varied in consistency with the adapted content and design principles described in the methodology. No written information ranked consistent for all points of clinical information. Three of the written information materials were rated consistent for "what is ROPEE", and only one to two were rated as consistent for "why ROPEE are important", "the procedure", and "what parents can do". None of the written information included information about "what parents can do".

For words and language rating, the Flesch–Kincaid readability score ranged from 49.1 to 72.2 (average: 58.6), which corresponded with a Flesch–Kincaid grade level that ranged from ages 12 to 22 years (average: 9.4–15 years). In the detailed analysis, complex words and medical jargon occurred in all seven information materials (e.g., vitreous, speculum, bradycardia) and less obvious medical jargon (e.g., dilate, ophthalmologist, neonate). Some medical jargon was considered necessary (e.g., retina) in materials; however, five of these mostly explained medical jargon (≦3 medical jargon words not explained) while two only sometimes explained medical jargon (≦6 medical jargon words not explained). In one, a sentence of capital letters was included, "CONTACT YOUR FAMILY DOCTOR", adversely affecting the tone of the written information. Additionally, it also used some outdated gendered language implying "he" will be the ophthalmologist. Another contained many brackets throughout the text that could have been explained in sentences (e.g., "[either weekly or two weekly whilst still in the unit]").

None of the written information included extensive use of te reo Māori. The only te reo Māori words included were the name of the hospitals and the mention of the word whānau in the title of one of the written information materials. Three of the written information materials contained Māori imagery. The whakapapa of the images was sought from the NICU involved. Identified whakapapa included the image of a bird with koru (fern shape) that was related to an overarching theme of the hospital. The borders contained a kōwhaiwhai (lattice) pattern that depicted growth, development and the interactions between a person and their environment. These connect the past to present using the knowledge and experiences of old and new to strengthen future generations and is the reason for inclusion in the written information. Other imagery appeared "medical textbook"-like, or conveyed little information in the image; for instance, an infant on its own. Of note, none of the materials provided information as to the whakapapa of the imagery.

In the design components, written information seldom emphasised text by use of bolding, italics or highlighting. Three contained little or no headings, which made it difficult to locate information. A table of contents was present in one online website; however, since all materials were short, a table of contents may not be necessary. The page layout and page text were variable. Two written information materials used the two columns of information recommended, while three (two digital sources and one printed leaflet) used one column of text, which made lines long and not preferable. Two of the printed leaflets had text sections that continued over to the next page, which was also undesirable when rated by good-design principles.

Discussion

This study highlights the variability of written information used in NICUs in Aotearoa to convey information to whānau around ROPEE, and it

Table 1: Summary comparisons of retinopathy of prematurity written information to recommended good-design principles.

20 good-design principles	Retinopathy of prematurity written information						
	1	2	3	4	5	6	7
Words and language **Medical jargon mostly explained** **Readability** Flesch–Kincaid grade level (FKGL) Flesch reading ease score	☆ ☆ FKGL: College (11.9) Flesch reading ease score: 49.1	☆ ☆ FKGL: 10th–12th grade (10.5) Flesch reading ease score: 52.8	☆ ☆ FKGL: 10th–12th grade (8.6) Flesch reading ease score: 57.7	☆ ☆ FKGL: 10th–12th grade (9.9) Flesch reading ease Score: 54.3	☆ ☆ FKGL: 10th–12th grade (10.0) Flesch reading ease score: 59.4	☆ ☆ FFKGL: 8th and 9th grade (7.8) Flesch reading ease score: 65	★ ☆ FKGL: 7th grade (7.2) Flesch reading ease score: 72.2
Tone and meaning Direct, informative and conversational	★ ★	★ ☆	★ ★	★ ★	★ ★	★ ★	★ ★
Voice and phrasing **Active voice** **No negations**	★ ☆ Some negations	★ ☆ Many negations	★ ★ Minimal negations	★ ★ No negations	★ ★ No negations	★ ☆ Some negations	★ ☆ Some negations
Sentence length Average sentence length <20 words	★ ☆ 22 words	★ ★ 18.4 words	★ ★ 13.6 words	★ ★ 16.9 words	★ ☆ 20.2 words	★ ★ 14.7 words	★ ★ 16 words
Font style **Text horizontal** **Sans serif font**	★ ★	★ ☆ Serif font	★ ★	★ ★	★ ★	★ ★	★ ★
Font size Within 10–12 point	★ ★	★ ★	★ ★	★ ★	★ ★	★ ★	★ ★

Table 1 (continued): Summary comparisons of retinopathy of prematurity written information to recommended good-design principles.

20 good-design principles	Retinopathy of prematurity written information						
	1	2	3	4	5	6	7
Colour and contrast **Black on white** **Coloured images**	★ ☆ Little colour	★ ★	★ ★	★ ☆ Little colour	★ ★ Dark on white	★ ★ Dark on white	★ ★ Dark on white
Line length and spacing Short lines, well spaced	★ ☆	☆ ☆ Long lines, closely spaced	★ ★	★ ☆ Long lines	★ ★	★ ★	★ ★
Paragraph length and spacing Short paragraphs, adequate spacing	★ ★	★ ☆ Close spacing	★ ★	★ ★	★ ★	★ ★	★ ★
Justification Justified left	★ ★	☆ ☆ Justified	★ ★	★ ★	★ ★	★ ★	☆ ☆ Justified
Organisation of content **Logical**	★ ★	★ ★	★ ★	★ ★ Mostly logical	★ ★	★ ★ Mostly logical	★ ★
White space Adequate space	★ ★	☆ ☆ Page cluttered	★ ★	★ ★	★ ★	★ ★	★ ★
Table of contents	☆ ☆	☆ ☆	☆ ☆	★ ★ Table of contents	☆ ☆	☆ ☆	☆ ☆

Table 1 (continued): Summary comparisons of retinopathy of prematurity written information to recommended good-design principles.

20 good-design principles	Retinopathy of prematurity written information						
	1	2	3	4	5	6	7
Headings **Clear headings**	★ ☆ One heading	☆ ☆ None	★ ★	★ ★	☆ ☆ None	★ ★	★ ★
Bullet points **Used to list rather than long paragraphs**	★ ☆	☆ ☆	★ ☆	★ ☆	☆ ☆	★ ☆	☆ ☆
Emphasising information **Important text bolded or highlighted**	☆ ☆ Incomplete	☆ ☆	☆ ☆	☆ ☆	★ ☆ Definition bolded	☆ ☆	☆ ☆
Page layout and page break **A4, portrait, 2 columns for information recommended**	Landscape, 3 columns	★ ☆ 1 column	★ ★	★ ☆ Digital, 1 column	★ ☆ Digital, 1 column	★ ☆ Landscape	★ ☆ Landscape
Repetition **Repetition absent**	★ ★	★ ★	★ ★	★ ★	★ ★	★ ★	★ ★
Paper **A4 page**	★ ★	★ ★	★ ★	☆ ☆ Not applicable	☆ ☆ Not applicable	★ ★	★ ★
Number of pages **Maximum of 1–2 pages** **Direction to further information**	★ ☆ 2 pages No direction	★ ★ 2 pages Non-specific direction	★ ★ 2 pages Direction	★ ★ 2 pages Direction	★ ☆ 2 pages No direction	☆ ☆ 3 pages No direction	★ ★ 2 pages Direction

Table 1 (continued): Summary comparisons of retinopathy of prematurity written information to recommended good-design principles.

20 good-design principles	Retinopathy of prematurity written information						
	1	**2**	**3**	**4**	**5**	**6**	**7**
Te reo Māori	Absent	Some present	Absent	Absent	Absent	Absent	Absent
Māori imagery	Absent	Manu koru	Kōwhaiwhai	Absent	Absent	Banner	Absent
ROPEE clinical information 1. What is ROP? 2. Why ROPEE are important. 3. The procedure. 4. What parents can do? 5. After the procedure.	☆ ☆ 1. Average 2. Poor 3. Good 4. Poor 5. Poor	★ ☆ 1. Poor 2. Good 3. Good 4. Good 5. Average	☆ ☆ 1. Good 2. Poor 3. Average 4. Poor 5. Average	☆ ☆ 1. Poor 2. Average 3. Poor 4. Poor 5. Poor	☆ ☆ 1. Poor 2. Poor 3. Poor 4. Poor 5. Poor	☆ ☆ 1. Good 2. Poor 3. Average 4. Average 5. Average	☆ ☆ 1. Good 2. Average 3. Average 4. Poor 5. Average

★ ★ Consistent with the adapted 20 good-design principles. ★ ☆ Somewhat consistent with the adapted 20 good-design principles. ☆ ☆ Not consistent with the adapted 20 good-design principles or not included.
ROPEE = retinopathy of prematurity eye examination; ROP = retinopathy of prematurity.

profiles the opportunities for future improvement and development of this information. Optimal communication with whānau provides openings to reduce whānau stress and support engagement and consent to ROPEE for lifelong eye health and wellbeing. Using tools such as the adapted good-design principles[11] to review the ROPEE written information in NICU units in Aotearoa enables NICU teams to consider opportunities for improvement when developing and implementing clinical tools such as written information. It is important that whānau receive sufficient clinical information to support informed decision making on consent for the ROPEE. Our results show that only 20% of the clinical information provided in the written information was rated as consistent (two stars). Previous research has shown that parents want and need detailed and written information that is complete and accurate.[2,3]

Most of the written information reviewed did not include widespread use of te reo Māori kupu and Māori imagery, required a high level of literacy and contained unnecessary medical jargon and abbreviations. Overall, information could be optimised to support informed consent. These factors provide unnecessary barriers to engaging with written information and reduce the ability for whānau to use the written information when deciding whether to consent for their infant(s) to undergo a ROPEE. Written health information that is engaging, informative and meaningful for Māori is an important strategy to contribute to health equity for Māori and uphold the principles of Te Tiriti o Waitangi.[21] The incorrect use of Māori cultural images along with technical and lengthy text can result in cultural disconnection.[22] For health information to be successful, it is essential that Māori input occurs with any redesign of written health information to ensure uptake and prevent cultural appropriation of imagery.[23] Examples of successful Māori-centred programmes include a Safe Sleep initiative involving all hospitals in Aotearoa.[24] Culturally appropriate written information was used in this programme successfully with a reduction in post-perinatal mortality by up to 29% for Māori.[24] The inclusion of Māori-oriented communication in future ROPEE written information will be of value in contributing to achieving health equity for Māori preterm infant health. Given that there is currently no national standardised ROPEE written information, the opportunity to design one meeting health literacy and whānau needs is imperative. If done well it will be a pro-equity tool that NICU clinicians can use with whānau Māori in the NICU.

If written information includes complex content (such as ROPEE), information may be discarded and not read, especially by those who have challenges with the dominant language or literacy.[8,25,26] Literacy is related to the readability of information provided and all the written information reviewed had a Flesch–Kincaid grade level above the recommended reading level of grade 6 (11 years old).[27] When creating written information, word complexity is important rather than the length of the word.[28] For example, the word examination has more syllables than dilate; however, dilate may be a harder word for some whānau to understand especially if English is not their first language.[29] Simplifying words and language—for example from ophthalmologist to "eye doctor"—is a strategy to increase readability. Low-literate individuals experience a high cognitive load when reading; therefore, having some information provided as images may alleviate this[26] and support informed consent processes.[30] The images in written information need to add value rather than be distracting, and there are opportunities for meaningful Māori imagery to be incorporated in written information to support information provision. Navigation of written information is important, and tools such as headings can be used to assist this;[31] however, our analysis indicates that headings were seldom used, making it difficult to locate information. Other challenges identified included the use of outdated gendered language; claiming "he" will be the ophthalmologist, demonstrating stereotypical attributes that doctors are male, which is incorrect.

The strengths of our study included the inclusion of all the written information (printed leaflets and web-based information) available within level 3 NICUs in Aotearoa. By doing so this provided the opportunity to learn from a diverse group of written information currently in use. ROPEE examinations also occur in level 2 units locally, once whānau are transferred home regionally, and there is the possibility that other localised written information is in use. However, the study highlights the variability present, and it could be postulated that this also occurs in smaller centres with smaller staff resourcing to develop resources for whānau. The lack of exploring whānau voices in this research is a limitation and it would be of interest to explore their experiences of written information and perspectives for future development as the end-users of such resources. It was not possible to discuss with the original authors

the processes for material development given the likely significant time and energy that would have been invested, often with limited resources within the health sector dedicated to such development.

The creation of new national ROPEE written information for Aotearoa that has appropriate content and design with optimal health literacy considerations will enhance these resources. The move towards more digitalised resources or apps on devices such as smartphones also needs to be considered. Future research is needed into the development and user testing of new written information on ROPEE involving whānau Māori in collaboration with whānau, and with a nationwide approach.

COMPETING INTERESTS
Nil.

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Audit of diabetes-related lower extremity amputations in the Northern Region of New Zealand 2013–2016

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ABSTRACT

AIMS: To characterise diabetes-related lower extremity amputations (DRLEA) and prior contact with specialist podiatrists in Northern New Zealand.

METHODS: Using administrative data, DRLEA ≥35 years were identified for the Northern Region (July 2013 to June 2016). For those domiciled in Metro Auckland (July 2015 to June 2016), additional clinical data described amputation cause, diabetes-related co-morbidities and podiatry contact.

RESULTS: There were 862 DRLEA for 488 people, including 25% (*n*=214) major amputations. Age-standardised amputation rates were three times higher for males than females (41.1 vs 13.6 per 100,000 population [95% confidence interval (CI): 37.3–44.9 vs 11.6–15.6 per 100,000] respectively). Amputation rates varied by ethnicity, being 2.8 and 1.5 times higher respectively for Māori and Pacific peoples than non-Māori, non-Pacific peoples. Mortality was high at 1-, 3- and 6-months post-admission (7.9%, 12.4 % and 18.3% respectively). There was high prevalence of peripheral vascular disease (78.8%), neuropathy (75.6%), retinopathy (73.6%) and nephropathy (58%). In the 3 months prior to first DRLEA admission, 65% were not seen by specialist podiatry.

CONCLUSIONS: Our study confirms higher DRLEA admission rates for Māori and males. We identified elevated rates among Pacific populations and observed suboptimal utilisation of specialist podiatry services.

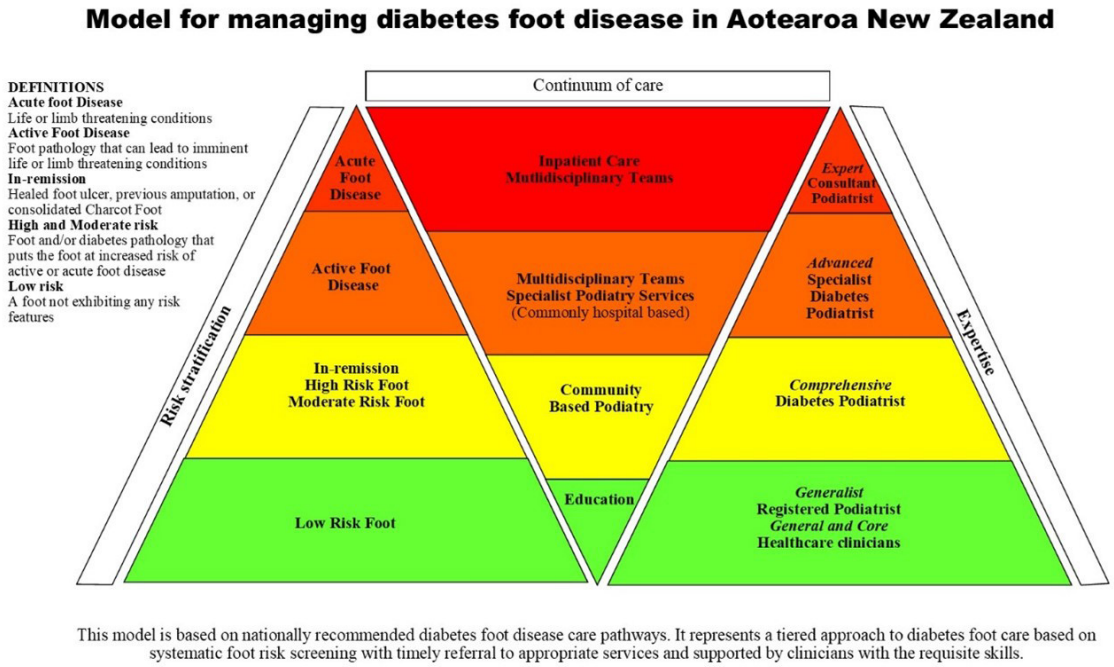
Diabetes is the leading cause of non-traumatic lower extremity amputation, both internationally[1] and in Aotearoa New Zealand.[2,3] Diabetes-related lower extremity amputations (DRLEA) are associated with demographic, socio-political and lifestyle factors, as well as broader microvascular and macrovascular complications.[4,5] Peripheral neuropathy, peripheral arterial disease (PAD) and a history of previous diabetes foot ulcers (DFU) or DRLEA are significant risk factors.[6] The majority of DRLEA are preceded by a DFU, with foot trauma being the predominate trigger for DFU.[5,7] In people with diabetes, the lifetime incidence of a DFU is estimated at 19% to 34%, of which 20% result in DRLEA.[1] Diabetes foot disease (DFD) contributes significantly to the global disability burden[1] and is associated with a 5-year mortality rate higher than for most types of cancers.[8,9]

With timely access to diabetes foot protection services and rapid referral of DFU to specialist foot services, encouragingly, many DFU and their potential sequalae can be avoided.[7,10] It is recognised that clinician adherence to clinical guidance and pathways can be suboptimal,[11,12] but early recognition of DFU is important as referral delays for first expert assessment have been associated with more severe ulcerations, additional and longer hospitalisations and more revascularisations and DRLEA.[13]

In New Zealand, well-organised diabetes foot protection services are recognised as an essential component of DFU and DRLEA prevention.[14] The services are predominately podiatrist-led and are commonly organised as depicted in Figure 1. It is expected that people with diabetes will be routinely screened for risk of foot ulceration and will access services in accordance with recommended pathways.[15] Diabetes foot services in the Northern Region are organised as depicted and adhere to nationally recommended pathways.

Despite a focus on optimising diabetes foot care,[16] DRLEA numbers continue to increase and there are variations in rates by age, gender, ethnicity and region.[2,3,17] We wanted to understand more about the characteristics of amputations in the Northern Region of New Zealand. The audit was undertaken as part of a

Figure 1: Model for managing diabetes foot disease in New Zealand.



Adapted from Garret M, Beeler E, Haggart P, et al. Competency Framework for Podiatrists and Healthcare Clinicians Working in Diabetes Lower Limb Care in Aotearoa/New Zealand [Internet]. New Zealand Society for the Study of Diabetes. 2020. pp. 8. Adapted with permission.
NB: The transverse lines between the triangles do not align, reflecting the potential overlap between risk and care intervention, as well as clinician expertise.

quality improvement project on behalf of the four Northern Region district health boards (DHBs) and the Northern Region Alliance Podiatry Network.

Aims

We sought to characterise DRLEA by age, gender, deprivation and ethnicity. For a subcohort we also aimed to further describe the causes of DRLEA and attendance at specialist podiatry services prior to amputation.

Methods

Study design

This was an observational descriptive study designed to audit the DRLEA in the Northern Region of New Zealand.

Setting

The Northern Region consists of four DHB areas: Northland (NDHB), plus three Metro Auckland DHBs—Auckland (ADHB), Waitematā (WDHB) and Counties Manukau (CMDHB).

Study population

People living in the Northern Region who underwent a DRLEA between July 2013 to June 2016 inclusive were identified from the National Minimum Dataset (NMDS) using *International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification 8th Edition* (ICD-10-AM) diagnostic and procedure codes.

People who had DRLEA in a Northern Region hospital who were domiciled to a DHB outside the Northern Region, or who had a DRLEA in a private hospital, were not included. People domiciled in the Metro Auckland area but who had a DRLEA in a public hospital elsewhere in New Zealand were included in the demographic analyses but excluded from the clinical care and service utilisation

analyses due to the unavailability of relevant clinical records.

Data sources

Information on DRLEA type, hospital admission demographics and date of death were obtained from the New Zealand Ministry of Health. For DRLEA that occurred in Metro Auckland July 2015 to June 2016, additional clinical and specialist podiatry service utilisation details were obtained from electronic hospital clinical records. Data collection was undertaken by diabetes services specialist podiatrists and medical registrars using a template developed by the authors and podiatry service team leaders. Collected data were randomly reviewed by the authors to ensure accuracy. Incomplete recording of critical events in one location resulted in the authors reviewing all clinical records from that location.

Statistics New Zealand's DHB projected population data and the New Zealand Virtual Diabetes Register 2016 estimates were used to calculate resident and diabetic population amputation rates respectively.

Definitions

Diabetes was defined by any ICD-10-AM codes E10–E14. Occurrence of a DRLEA was determined using Ministry of Health reporting operation procedure codes. Retinopathy and neuropathy were deemed present if they were either ICD-10 coded in the NMDS or identified as present in the clinical notes audit. Amputation was defined as major, proximal to the ankle, or minor, occurring at or distal to the ankle. A diagnosis of PAD was defined as present if a clinical diagnosis of PAD, or a previous history of revascularisation procedures, or a reported ankle-brachial index of ≤0.9 or ≥1.3 or a toe-brachial index ≤0.70 was noted in the clinical record. Renal replacement therapy was defined as present when identified from the clinical record and diabetic nephropathy was defined by ICD-10-AM codes. Pre-amputation contact with a specialist podiatry service was defined as attendance within 3 months before the admission date, considering an average 12-week DFU healing time, to capture relevant specialist podiatry contacts.

Statistical methods

Age-standardised rates (ASR) of admission for DRLEA in people with diabetes were calculated for the Northern Region and Metro Auckland resident populations aged ≥35 by gender and ethnicity. Rates were standardised to New Zealand's population in 2015. A cutoff of ≥35 years was used to align with other DHB diabetes indicators. Average age at discharge and age-group specific admission rates were also calculated. Admissions were examined by domicile and deprivation, using the New Zealand Index of Deprivation 2013 (NZDep2013) quintile index of socio-economic deprivation as a proxy marker for socio-economic status.[18] ASR by NZDep2013 quintile were not calculated as projected estimates for DHB populations were not available at the time of data analysis. Mortality rates at 1, 3 and 6 months were calculated by admission using the date of last amputation procedure prior to date of death. Type of amputation and length of stay (LOS) were also analysed.

Additional analyses carried out for the Metro Auckland DHBs for the July 2015 to June 2016 cohort focussed on clinical risk factors associated with DRLEA, including PAD, neuropathy, retinopathy and diabetic nephropathy. Amputation cause, critical event leading to amputation and specialist podiatry attendance prior to amputation were also examined.

Being an audit, this project was considered low risk and reviewed under the expedited ethics pathway. Obtaining individual consent was waivered. To protect privacy, data were de-identified and allocated a unique identifier prior to data analysis and then aggregated. Ethics approval was granted from the Central Health and Disabilities Ethics Committee (reference 16/CEN/181/AM01).

Results

Northern Region cohort

There were 863 amputations performed on 488 people with a total of 635 admissions. Approximately 22% (*n*=107) of people experienced more than one admission over the 3-year period. The average LOS for DRLEA hospital admission was 18.2 days.

Minor amputations were most common, making up 75% (n=649) of DRLEA, and major amputations accounted for 25% (*n*=214). See Table 1.

The number of DRLEA admissions remained stable for the 3-year period (see Table 2 for numbers and demographic details). Mortality was high: in 7.9% (n=50) of admissions the person had died within 1 month of amputation, 12.4% (n=79) at 3 months and 18.3% (n=116) at 6 months.

The 3-year ASR for admissions for DRLEA in the resident Northern Region population ≥35 years

Table 1: Number of amputations by type for the Northern Region and Metro Auckland.

Code	Description	Northern Region	Metro Auckland
4433800	Amputation of toe	336	281
		38.9%	***38.9%***
4435800	Amputation of toe including metatarsal bone	268	231
		31.1%	***32%***
4436400	Midtarsal amputation	14	13
		1.6%	***1.8%***
4436401	Transmetatarsal amputation	31	27
		3.6%	***3.7%***
4436701 4436700	Disarticulation at knee Amputation above knee	102	80
		11.8%	***11.1%***
4436702	Amputation below knee	112	91
		13.0%	***12.6%***
Total		**863**	**724**

was 26.3 per 100,000 (95% confidence interval [CI] 24.2–28.3).

By gender the rate was three times higher in males than females at 41.1 per 100,000 resident population (95% CI 37.3–44.9 per 100,000) for males and 13.6 per 100,000 (95% CI 11.6–15.6 per 100,000) for females.

The mean age for DRLEA was 65 years. The 5-year age group specific rates per 100,000 population increased with age until 75–79 years. Concerningly, 6.8% (n=43) of DRLEA admissions occurred in individuals under the age of 45 years. The mean age of females on discharge post-DRLEA was 63.2 years compared to males at 65.7 years. Pacific people and Māori were a decade younger (mean age 59.9 and 60 years respectively) than the rest of the population (mean age 69.7 years).

There was also variation of amputation admission rates by ethnicity (Figure 2). The average ASR per 100,000 resident population aged 35 years and over was higher for Māori and Pacific people than non-Māori, non-Pacific people (75.9, 95% CI 63.8–88.1; 81.6, 95% CI 68.5–94.7; 16.1, 95% CI 14.3–17.8 respectively). The difference is also apparent in the rates for the estimated diabetes population, being 2.8 times higher for Māori (356.9, 95% CI 300–413.8) and 1.5 times higher for Pacific people (197.1, 95% CI 165.4–228.7) compared to non-Māori, non-Pacific people (127.8, 95% CI 113.9–141.6).

The number of people undergoing a DRLEA by NZDep2013 quintile was notably higher for those living in quintile 5 (the most deprived), with the number almost equal to the total numbers in the other four quintiles combined (311 and 319 respectively).

Metro Auckland cohort

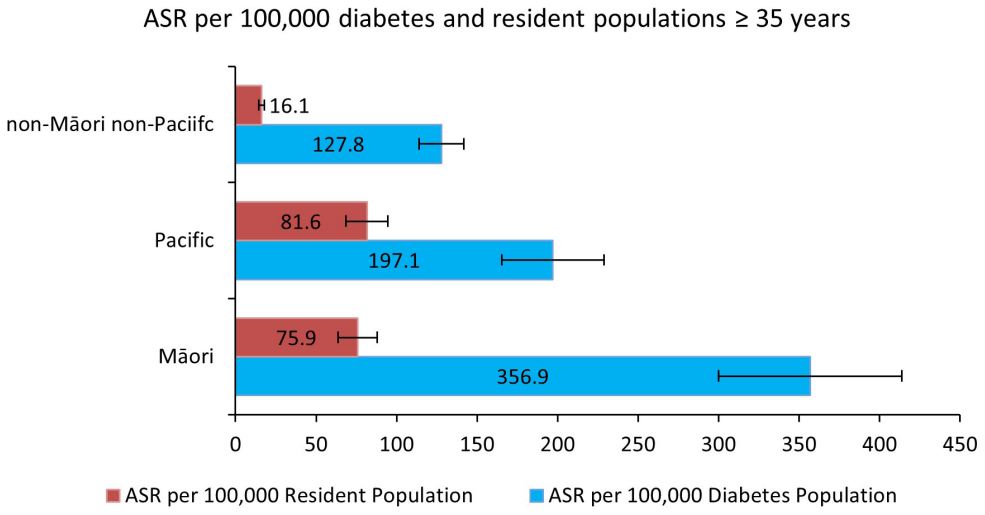
In the Metro Auckland 1-year July 2015–June 2016 cohort, there were 193 DRLEA-related admissions. Of these 27.5% (n=53) were female and 72.5% (n=140) were male. The prevalence of comorbidities was high, with retinopathy recorded in 73.6% (*n*=142) of admissions, neuropathy in 75.6% (*n*=146), PAD in 78.8% (*n*=152), diabetic nephropathy in 58% (*n*=112) and 21% (*n*=41) on renal replacement therapy.

Most amputations were multifactorial in cause, with underlying wounds/ulcers (n=147, 76.1%) and infections (n=111, 57.5%) documented in most cases. Foot ulcers, skin infection, ischaemia and osteomyelitis were noted as precursors to

Table 2: Demographic data—admissions for DRLEA for the Northern Region by year.

	2013–2014	2014–2015	2015–2016	Total	Proportion
Northern Region					
Total admissions	205	203	227	635	100%
Male	158	136	166	460	72.4%
Female	47	67	61	175	27.6%
Māori	53	57	45	155	24.4%
Pacific	48	43	60	151	23.8%
Asian	6	17	18	41	6.5%
European/Other	98	86	104	288	45.4%
Quintile 1	16	7	23	46	7.2%
Quintile 2	26	23	26	75	11.8%
Quintile 3	28	31	25	84	13.2%
Quintile 4	29	43	42	114	18.0%
Quintile 5	103	97	111	311	49.0%
Age <=44	10	20	23	43	6.8%
Age 45–64	84	71	95	250	39.4%
Age 65–74	59	52	65	176	27.7%
Age 75–84	43	46	44	133	20.9%
Age 85+	9	14	10	33	5.2%

Figure 2: Average age-standardised rate per 100,000 2015 DHB resident/diabetes populations aged 35 and over for admissions for DRLEA July 2013–June 2016 by ethnicity for the Northern Region.



amputation. The specific type of foot trauma or critical event leading to wounds/ulcers was inadequately documented, with a clear critical event ascertainable in only 34.7% (n=67) of admissions. Underlying critical events that were identified include: non-healing amputation site (n=14), trauma (n=10), footwear (n=9), pressure injury (n=8), abscess (n=5), toenail-related (n=4), burns (n=4), foreign body (n=4), broken or cracked skin (n=3), fall (n=3) and fracture (n=3).

In 45% (*n*=87) of admissions the patient was seen by specialist podiatry services in the 3 months prior to amputation, decreasing to 35% (n=47) when examined by first admission within the 3-year study period. Age, ethnicity and gender did not appear to influence access to specialist podiatrist care.

Discussion

The study identified a consistent DRLEA admission rate over the observation period, with 75% being minor amputations. Approximately 20% experienced multiple admissions within the 3 years. Amputation admission rates increased with age, but occurrences were also noted in younger age groups. Males, Māori and Pacific people faced elevated admission rates for DRLEA. High numbers of DRLEA were observed with higher levels of deprivation. Furthermore, Māori and Pacific populations underwent amputations approximately a decade earlier than other groups. High mortality rates were observed at 1, 3 and 6 months. However, due to the limited cohort size, these rates may not be generalisable to the broader New Zealand population.

The prevalence of microvascular related comorbidities of retinopathy, neuropathy and diabetic nephropathy was high, as was PAD. It was often difficult to ascertain a primary cause of DRLEA; however, common precursors were evident with foot ulcers, skin infection, ischaemia and osteomyelitis being noted. Approximately 65% of people admitted had not been seen by specialist podiatry services leading up to their first amputation. People admitted for a subsequent amputation were more likely to have prior podiatry contact.

The steady rate for all DRLEA in this study differs from an OECD report that noted a greater than 25% decline in major amputations for 2000–2012 for some countries including New Zealand, with minor amputation rates starting to increase.[19] It will be interesting to see if future reporting on DRLEA from the OECD also shows a slowing or flattening of the rate of amputation.

This study revealed a high 1-month mortality rate of approximately one in 12, doubling to almost one in five at 6-months—a trend consistent with the broad range of 4% to 22% reported in a systematic review on hospital 30-day mortality rates for all amputations.[20] This finding potentially reflects the high comorbidity burden, aligning with other studies that link comorbidity and mortality in individuals undergoing lower limb amputation.[2,5,20] Yet a New Zealand study did not establish a clear link with comorbidity; instead, it identified age and Māori ethnicity as independent factors linked to increased risk.[21] Many other factors also influence mortality rates, including patient status, the level of amputation, health provider decisions and patient preference.[20] However, mortality rates in this study were not adjusted to report on the influence of these factors.

Our results indicating higher rates of DRLEA in males is in keeping with other New Zealand and international studies, but the reasons why remain unclear.[2,3,5,22,23] While differences may be due to differences in health-seeking behaviours, the proportions seen by podiatrists prior to DRLEA were similar. More likely reasons are the higher cardiovascular risk of for men, higher smoking rates[24] and potentially the type of occupation and associated footwear.

There is an established correlation between increasing age and heightened risk of DRLEA,[5] which this study reaffirms. Yet it was disconcerting that 6.8% of severe end-stage complications occurred in younger individuals, as this can signal poor diabetes outcomes and associated diminished quality of life, and potentially reduced life expectancy. The prevalence of type 2 diabetes is rising in teenagers and young adults and is more likely to affect Māori and Pacific populations.[25] This age group is also more likely to develop microvascular complications, including neuropathy, which is a significant risk factor for earlier DRLEA.[26]

Higher DRLEA admission rates for Māori and Pacific people are evident when examining rates against both the general and diabetes population. The higher rate in our audit of DRLEA for Pacific people differs from other New Zealand studies that found Pacific people had a lower rate than European/other ethnicities.[2,3] Undercounting of Pacific peoples in the denominator data sources would inflate these rates.[27] Ethnic disparities including higher DRLEA rates for Indigenous populations have also been found

in international studies, but the cause remains unclear.[4,28] It is postulated that ethnic disparities could be related to socio-economic factors and comorbidities; however, other New Zealand studies have demonstrated an enduring disparity after adjusting for these variables.[2,3] Distal effects of colonisation, institutional racism and cultural competency of clinicians may contribute to health inequalities.[29,30] This was unable to be evaluated in this study. As noted by others, there was a likely correlation between worsening deprivation levels and higher numbers of DRLEA, probably linked to the corresponding higher prevalence and burden of diabetes for those living in higher levels of socio-economic deprivation.[6]

Ulcers being present in 76.1% of DRLEA is consistent with other research.[5] However, documentation of the critical event of DFU was insufficient, recorded in only 34.7% of admissions. Foot trauma, a major contributor to DFU and DRLEA, was noted as an underlying cause in a third of cases, significantly lower than the expected 80%. The under-reporting of foot trauma may be due to prolonged DFU duration before amputation, affecting event recall. Accurate recording of critical events is crucial, not only for clinical understanding but also for accessing funding pathways for wound care and patient rehabilitation.

Findings from this study indicate that people with diabetes-related foot complications may not be receiving timely access to specialist podiatry services, with only 35% of admissions being seen prior to first DRLEA admission. This finding is similar to another New Zealand study that reviewed care before and after admission for a DFU and reported only 33% were seen by specialist foot services.[11] The low number seen is cause for concern, indicating referral patterns and behaviours that are contrary to national recommendations of early referral to specialist foot services.[14,15] This may be a contributing factor to our high DRLEA rates compared to countries with similar healthcare systems, such as Australia and the United Kingdom.

Strengths and limitations

This study uses a well-curated national hospital discharge dataset, ensuring reliable documentation of amputations in New Zealand hospitals. Clinical note reviews were conducted by experienced clinicians using local electronic clinical records, with author oversight for accuracy. Identifiable data allowed verification of amputation procedures and comorbidities against the clinical record, enabling differentiation between single and multiple amputations in one person.

However, potential under-estimation of the total proportion of people having multiple admissions may exist due to exclusion of admissions outside the study period. The ASR by NZDep2013 quintile was not calculated due to unavailability of appropriate projections for DHB populations during the study analyses.

While the study examined all DRLEA, rates were calculated for those ≥35 years, introducing variation in age thresholds between studies. Approaches to calculate resident and diabetes populations also vary across countries and studies, making comparisons challenging.[19] We reported on admissions for DRLEA complicating direct comparisons with studies reporting numbers and rates.

Conclusion

This study adds to local knowledge regarding DRLEA in the Northern Region of New Zealand with the audit being undertaken to inform service development. Our findings of higher rates of DRLEA admission rates for Māori and males is consistent with other studies. The finding of high rates for Pacific people is new. Referral to expert podiatrist care for acute diabetes foot problems needs to be improved. The findings reinforce the need for further work to combat these health inequities and improve diabetes foot-related outcomes.

COMPETING INTERESTS
The authors declare no competing interests.

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This audit would not have been possible without the support of the Northern Region Alliance Diabetes and Podiatry Advisory groups, Metro Auckland district health boards and primary health organisations and the podiatry teams and clinicians within the secondary services diabetes teams. All graciously gave time and helped with data extraction and clinical note audit. We hope people find the audit results helpful for guiding quality improvement initiatives for people with diabetes at risk of diabetes foot disease.

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Appendix

Appendix Table 1: Numbers of admissions and lower limber amputation (LLA) procedures in people with diabetes.

	2013–2014	2014–2015	2015–2016	Total
Northern Region				
Number of admissions for a LLA	205	203	227	635
Number of LLA procedures*	290	269	303	862
Metro Auckland				
Number of admissions for a LLA	162	168	193	523
Number of LLA procedures*	240	221	262	723

*Limited to the first 20 procedure codes per admission.

Appendix Table 2: Age-specific rates per 100,000 resident population for DRLEA for the Northern regions.

5-year age groups	Rates of DRLEA admissions per 100,000 population
35–39	1.5
40–44	8.3
45–49	10.3
50–54	16.2
55–59	22.0
60–64	36.2
65–69	47.9
70–74	47.0
75–79	78.9
80–84	78.9
85+	46.3

Table 3: Rates for admissions for DRLEA for the Northern Region and Metro Auckland.

	Northern Region	**Metro Auckland**
Resident population		
2013–2014	**26.4**	**23.5**
95% CI	*22.7–30*	*19.9–27.2*
2014–2015	**25**	**23.9**
95% CI	*21.5–28.5*	*20.2–27.5*
2015–2016	**27.4**	**26.8**
95% CI	*23.9–31*	*23.0–30.6*
Total	**26.3**	**24.9**
95% CI	*24.2–28.3*	*22.6–26.9*
Diabetic population		
2013–2014	**174.2**	**159.3**
95% CI	*150.3–198.1*	*134.7–183.9*
2014–2015	**179.3**	**169**
95% CI	*154.3–204.3*	*143.2–194.7*
2015–2016	**193.6**	**183.6**
95% CI	*168.3–218.9*	*157.5–209.6*
Total	**182.4**	**170.7**
95% CI	*168.1–196.6*	*156–185.4*

Epidemiology and diagnostic challenges of anti-NMDAR encephalitis: a study from the Waikato region

Pablo Richly, Beatriz Romero Ferrando

ABSTRACT

AIMS: Anti-NMDAR encephalitis is an increasingly recognised autoimmune disorder with evolving diagnostic criteria. This study aims to analyse the prevalence and diagnostic patterns of anti-NMDAR encephalitis in a New Zealand hospital setting.

METHODS: Data from Waikato Hospital's lab database, encompassing anti-NMDAR antibody requests between August 2013 and July 2023, were examined. Cases were categorised based on age, gender and diagnostic outcomes.

RESULTS: In all requests, 288/318 (91%) were processed and 10/288 (3.5%) anti-NMDAR antibodies were positive. Positive cases were equally frequent by sex, with an average age of 29.4 years. Only 6/10 were diagnosed with anti-NMDAR encephalitis, while others received alternative diagnoses. Māori ethnicity was overrepresented. This study indicates a low prevalence of anti-NMDAR encephalitis in the Waikato region, with adult predominance. Ethnic disparities were observed. The need for refining testing criteria to optimise cost-effectiveness is discussed.

CONCLUSION: Anti-NMDAR encephalitis is relatively rare in Waikato Hospital, New Zealand, with diagnostic challenges related to testing criteria and ethnic diversity. Further research and consideration of testing protocols are warranted.

Anti-NMDA receptor encephalitis is increasingly recognised, with over 100 cases reported in the literature, yet its true prevalence remains unknown.[1] The first comprehensive description of anti-NMDAR encephalitis was provided in 2007.[2] However, the criteria for diagnosing this condition were not established until 2016.[3] Over the last two decades, the aetiology of encephalitis has shifted from infections as the primary known cause to the identification of multiple autoantibodies in encephalitis patients. Liem et al. discovered that autoimmune encephalitis in New Zealand was led by anti-LGI1 antibodies, followed by anti-NMDAR antibodies, in patients aged 15 and older presenting with encephalitis.[4]

In a recent systematic review, it was described that psychiatric symptoms were reported in 1,050/1,100 (95%) anti-NMDAR encephalitis patients, but only 52/1,100 (5%) had isolated psychiatric features.[5] Further research showed that anti-NMDAR antibodies were not found in patients with a First Episode of Psychosis unless they had anti-NMDAR encephalitis. It was concluded that warning signs and criteria for autoimmune psychosis have limited utility when neurologic symptoms are absent or paraclinical tests are normal.[6]

Clinically, anti-NMDAR encephalitis presents with a prodromal phase, including fever and viral-like symptoms such as headaches. After a few days, this is followed by a multistage progression of psychiatric manifestations, abnormal movements, seizures, sleep difficulties, language dysfunction and autonomic instability. Mutism, catatonic postures and decreased levels of consciousness might follow.

Both brain MRI and lumbar puncture are usually unremarkable, especially at the onset of symptoms. EEG readings are often slow and can show a characteristic delta brush pattern. These test results can be non-specific, making antibody testing crucial for confirming the diagnosis.

While anti-NMDAR antibodies are consistently found in the CSF of patients, they are absent in approximately 20% of serum samples. Serum NMDAR-antibodies test positive in 3% of both healthy and disease controls, leading to so-called "clinically irrelevant" results. Consequently, the absence of CSF positivity in this context is considered indicative of a lack of direct autoantibody pathogenicity.[3]

A study in Japan found that among children who met the probable criteria for anti-NMDAR encephalitis, 32% (13/41) tested positive for anti-NMDAR antibodies when requested. In contrast, only 3% (3/96) of those who did not meet the criteria tested positive for these antibodies. Most

false-positive diagnoses were associated with neurologic autoimmunity.[7] In a retrospective study of 221 adult patients with clinically suspected autoimmune neurological disorders, anti-NMDAR antibodies were detected in 85% (34/40) of patients meeting the probable criteria, while they were detected in only 3% (5/180) of patients not fulfilling the criteria.[8] A prospective study with admitted patients who fulfilled criteria for possible autoimmune encephalitis and/or red flags along a time window of 7 years found a positivity rate of 65% (100/160).[9] Although psychiatric symptoms were frequent, after multivariate analysis, the clinical hallmarks of anti-NMDAR encephalitis seemed to be catatonia–delirium comorbidity, tonic-clonic seizures and orolingual dyskinesia.[9]

Method

An audit (CASU # 4471P) was conducted with retrospective data from Waikato Hospital's lab database, identifying patients with suspected encephalitis and anti-NMDAR antibody requests between August 2013 and July 2023. An Excel spreadsheet was used for data collation and analysis. Based on the HDEC screening form, the audit was out of scope and did not require HDEC approval.

Results

Over 10 years, 318 lab requests were made, of which 286 were for patients 18 years old or older. However, 30/318 (9%) of the requests were not tested or analysed (Table 1). The primary cause for this occurrence for 20/30 (60%) was the unavailability of a mandatory neurologist review. The remaining instances were not processed due to laboratory registration errors (4/30), or because an inadequate or unsuitable sample was received for the requested test (6/30).

The 10 anti-NMDAR antibodies positive cases were equally frequent by sex, with an average age of 29.4 years (range from 0 to 81). Only 6 out of 10 positive cases were diagnosed as anti-NMDAR encephalitis. The remaining cases received alternative diagnoses, such as Neuromyelitis spectrum disorder, HSV-1 encephalitis, progressive ascending lower motor neuron process of uncertain aetiology and chronic schizophrenia. While most anti-NMDAR encephalitis cases' ethnicity was identified as European, 2/6 were Māori.

The main clinical features present in the six anti-NMDAR encephalitis cases were: movement disorders, dyskinesias or rigidity/abnormal postures (5/6), abnormal behaviour or cognitive dysfunction (4/6), decreased level of consciousness (4/6), autonomic dysfunction or central hypoventilation (2/6), speech dysfunction (1/6), seizures (1/6). Additionally, 3/6 (50%) cases presented a concomitant teratoma.

Discussion

At Waikato Hospital, requests for anti-NMDAR antibody testing require review by a neurologist, but meeting the probable criteria for anti-NMDAR encephalitis is not mandatory. This is consistent with findings from other countries in the last decade for patients clinically suspected of having autoimmune encephalitis, despite not fulfilling the probable criteria.[1] Notably, in our study merely one out of 48 tested patients received a diagnosis of anti-NMDAR encephalitis. The present audit suggests that anti-NMDAR encephalitis would be likely rare in the Waikato District Health Board (DHB), occurring at a rate of 0.6 cases per year at Waikato Hospital and being more prevalent among adults. The crude incidence estimate for NMDAR encephalitis in the DHB would be 0.14 cases per 100.000 person/year. Māori ethnicity was overrepresented in our sample, but due to the small number of cases, this finding might not be conclusive.

Our findings are limited to the tests requested for inpatients at Waikato Hospital, so cases in the community or other healthcare facilities would be missing, potentially affecting the validity of our conclusions.

Given the low incidence of clinically suspected encephalitis confirmed as anti-NMDAR encephalitis, the cost-effectiveness of stricter testing approval criteria is worth considering when autoimmune psychosis is suspected.

Table 1: Anti-NMDAR antibody requests (August 2013 to July 2023).

	Total	Adults	Under 18
Requested	318/318 (100%)	286/318 (90%)	32/318 (10%)
Tested	288/318 (91%)	257/286 (90%)	31/32 (97%)
Detected	10/318 (3%)	9/286 (3%)	1/32 (3%)
Diagnosed	6/318 (2%)	6/286 (2%)	0/32 (0%)

Table 2: Probable anti-NMDAR encephalitis criteria.[3]

1. Rapid onset (less than 3 months) of at least four of the six following major groups of symptoms: a. Abnormal behaviour or cognitive dysfunction b. Speech dysfunction (pressured speech, verbal reduction, mutism) c. Seizures d. Movement disorders, dyskinesias, or rigidity/abnormal postures e. Decreased level of consciousness f. Autonomic dysfunction or central hypoventilation.
2. At least one of the following laboratory study results: a. Abnormal EEG (focal or diffuse slow or disorganised activity; epileptic activity, or extreme delta brush) b. CSF with pleocytosis or oligoclonal bands.
3. Reasonable exclusion of other disorders* a. The diagnosis of probable anti-NMDAR encephalitis can also be made in the presence of three of the above group of symptoms and identification of a teratoma. b. The diagnosis of definite anti-NMDAR encephalitis can be made in the presence of three of the above group of symptoms and IgG anti-GluN1 NMDA receptor antibodies after reasonable exclusion of other disorders.

COMPETING INTERESTS
The authors declare that there is no conflict of interest.

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Prevalence of urinary incontinence in New Zealand women from the cross-sectional Sexual and Reproductive Health module of the New Zealand Health Survey 2014/2015

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ABSTRACT

AIMS: To describe urinary incontinence prevalence for New Zealand women.

METHODS: The New Zealand Health Survey Adult Sexual and Reproductive Health module 2014/2015 was used to estimate urinary incontinence prevalence. Associations between urinary incontinence and age, body mass index (BMI), parity and ethnicity were estimated by logistic regression adjusted for sampling weights.

RESULTS: There were 2,472/5,685 (43.5%) of women aged between and 16 and 74 who responded to the urinary incontinence question and reported at least some incontinence. The sample survey weight-adjusted prevalence (95% confidence interval) was 41.7% (40.0–43.4). An increased prevalence of incontinence was seen with older age, increased BMI and greater parity. The association between BMI and parity was complex, with the lower prevalence with lower BMI attenuated with increasing parity. After adjustment for these variables there was no association with incontinence prevalence for Māori versus non-Māori or European versus non-European.

CONCLUSIONS: Urinary incontinence is highly prevalent in New Zealand women. There was no association with ethnicity after adjusting for older age, increased BMI and parity. The prevalence identified in the New Zealand Health Survey is higher than that reported in older surveys based on the electoral roll.

Urinary incontinence is the complaint of involuntary urinary loss. It is a bothersome condition that is strongly associated with reduced quality of life.[1]

Most of the research in this area in New Zealand is relatively old and difficult to interpret in the context of the changing New Zealand population structure with respect to age and ethnicity. There has been a decline in parity of New Zealand women over the last 30 years, particularly for Pākehā, and this may influence prevalence estimates. Diabetes and obesity have increased in prevalence over recent decades, and this may also have substantially affected the prevalence of continence problems overall, and within different ethnic groups. Continence problems affect both men and women and there is little published information about the prevalence of urinary incontinence in men in New Zealand. The past research comprises regional surveys, all based on random samples of local electoral roll, from Gisborne,[2] Dunedin[3] and Wellington.[4] The Gisborne study (1985) was of people over the age of 65 years, with the definition of urinary incontinence as a positive response to the question "*Have you ever wet yourself?*" in a face-to-face interview. For this study 11.6% of respondents reported incontinence. The Dunedin study (1988) was a phoned interview of a sample of women from the electoral roll. The overall prevalence of urinary incontinence was 31%. Only 35% of this sample had sought help. The Wellington study (1994) was a postal questionnaire with phoned follow-up of a sample of women. The overall prevalence of urinary incontinence was 34%. There was higher prevalence in Māori (47%) and European (31%) compared to Pacific women (29%).

The authors recently gave advice to the Ministry of Health New Zealand Health Survey design team about specific questions for the planned 2024 New Zealand Health Survey and through these discussions learned that the urinary incontinence questions from the 2014/2015 survey have never been published.

The aim of this study is to estimate the prevalence of any urinary incontinence in women

in New Zealand and to explore associations with age, ethnicity, body size and parity based on the unpublished New Zealand Health Survey urinary incontinence data.

Methods

The full methodology of the New Zealand Health Survey and the Adult Sexual and Reproductive Health module are available on the Ministry of Health – Manatū Hauora website.[5,6]

In brief, this is a sample survey that is carried out annually, with the main survey collecting standardised information from a set of core questions, and is administered to adults aged 15 years and older face-to-face and by computer-assisted techniques. In addition, separate "modules" focussing on specific conditions are also administered, and for this report the data summaries and analyses are based on the urinary incontinence questions in the Sexual and Reproductive Health module. The continence questions comprised two questions: about frequency of incontinence in relation to month, week and day; and amount of incontinence, categorised as "a few drops", "enough to wet your underwear", "enough to wet your outer clothing" and "enough to wet the floor." These questions were based in turn on questions from the United States of America's Nurses Health Study 2003. These questions were only asked of female participants. The sample selection was a multi-stage, stratified, probability-proportional-to-size design of approximately 13,000 adults and 4,500 children, and a dual frame approach was used with an area-based sample using "meshblocks" and a list-based electoral roll sample. Exclusions from the survey population are specific types of non-private dwellings, which includes hospitals, dementia care units, hospital-level care in aged care facilities and very remote and sparsely populated areas. The final weighted response rate was 79% for adults.

Ethnicity group variables used the concept of "total response ethnicity", meaning that survey respondents can appear in and contribute to statistics for more than one ethnic group; and these were summarised by Māori, Pacific, Asian and European/Other, the latter including mainly Middle-Eastern, Latin-American and African ethnicities, and those who answered "New Zealander". For age, this was grouped in the survey into three bands: 16–29 years, 30–49 years and 50–74 years. For body size, this was grouped in categories in relation to body mass index (BMI) as <18.5, 18.5–25, 25–30 and >30kg/m^2. The variable used for parity was the numeric response to the question "*How many live children have you given birth to*" with parity of 3 or more treated as one category.

Access to the data used in this study was provided by Statistics New Zealand under conditions designed to keep individual information secure in accordance with requirements of the *Data and Statistics Act 2022*. The opinions presented are those of the authors and do not necessarily represent an official view of Statistics New Zealand.

The data tabulations include both the raw counts and proportions, and the proportions estimated after accounting for sampling weights. For analysis purposes we have opted to use "any incontinence" as the measurement of incontinence and we describe the associations between urinary incontinence, age band, BMI category, parity and ethnicity, with logistic regression, also accounting for sampling weights. We give a summary of the proportion of participants with incontinence in relation to how often participants reported they had incontinence. Interaction terms are used to explore if associations between urinary incontinence and age band depend on BMI or parity. If the interaction p-value is not significant then main effects are reported for comparison of age bands with the youngest band and for ethnicity, BMI or parity, each adjusted for age band. If the interaction p-value is significant then there is evidence that the association between incontinence and age band depends on BMI or parity. The associations with ethnicity are shown after adjustment for age band, BMI and parity, and their two-way interactions. This is shown for Māori versus non-Māori and European versus non-European.

SAS 9.4 was used for analyses, and in particular "Proc Samplefreq" for estimation of prevalence and "Proc Samplelogistic" for the sample weight-adjusted logistic regression analyses of associations between continence and age, body size, parity and ethnicity.

Results

The numbers of participants answering each general section varied: 5,685 had data on age, 5,377 on BMI and 4,214 on parity. The prevalence estimates for any urinary incontinence by age band and BMI category, age band and parity, and

parity and BMI category are shown in Tables 1–3. Prevalence by these variables is also shown in Figure 1. Among those with any incontinence, 1,022/2,472 (41%) had incontinence less than monthly, 1,076 (47%) at least once a week up to monthly and 374 (15%) daily. As shown in Table 4 there was no evidence of a two-way interaction between age band and BMI category (P=0.49) or age-band and parity (P=0.14) but there was evidence of an interaction between parity and BMI category (P<0.001), and for a main effect of age (P=0.04). For the main effect of age, both the older age bands had a greater probability of having incontinence compared to the youngest age category, with an odds ratio for association of about 1.5 for both older age bands. The relationship between parity and BMI category was more complex. In general, those in the lowest BMI category (<18.5) had a lower probability of incontinence compared to those in the 18.5–25 category, although the strength of this association weakened as parity increased. The prevalence in the lowest BMI category for those with a parity of 0 was not able to be estimated due to low cell counts. In general, those in the higher BMI categories had a higher probability of incontinence compared to those in the 18.5–25 category, although the strength of this association was not as strong when parity was in the categories of 1 or 2 for those in the BMI category of 25–30. In general, higher parity was associated with a greater probability of incontinence although this was most marked when moving from parity 0 to 1, and a smaller increase in probability from 1 to greater parity.

Because of the way ethnicity was categorised it was not possible to model ethnicity in mutually exclusive categories; however, because of the effect of age identified in the analysis above, Table 5 shows prevalence estimates for urinary incontinence by ethnicity and age band. Estimated prevalence by ethnicity and age is also shown in Figure 2. In a logistic regression model, there was no evidence of an interaction between Māori ethnicity versus non-Māori and any of age (P=0.22) or BMI category (P=0.78) and a weak association with parity (P=0.02). Table 6 shows associations of incontinence with ethnicity after adjustment for the other possible predictors of incontinence: age, BMI and parity. After adjustment for the other effects there was no evidence that Māori had a higher probability of incontinence. In a similar model, there was no evidence of an interaction between European ethnicity versus non-European and any of age (P=0.41), BMI category (P=0.18) or parity (P=0.36), and the main effects associations are also shown in Table 6. There was also no evidence of an association between European versus non-European ethnicity and urinary incontinence after adjustment for the other variables.

Discussion

The complaint of any urinary incontinence is highly prevalent in New Zealand women, with an overall prevalence of over 50% in women aged between 50 and 74 years, although the complaint was also prevalent in the younger age band—women aged between 16 and 29 years—at around 21%. Incontinence severity was more than monthly for about 60% of those with incontinence. There was evidence that incontinence prevalence increased with older age, greater BMI and greater parity, although the effect of parity also depended on BMI, with the lower prevalence of incontinence with BMI <18.5 being attenuated with greater parity. The presence of incontinence was not associated with ethnicity after adjustment for other possible predictors of incontinence: age, BMI and parity.

The strengths of this analysis are the high response rate, about 80%, and the representative sample with appropriate weighting in relation to the sampling process. There was good representation of different ethnicities. Weaknesses of the data are that it did not include those in very old age ranges or those living in residential care, that the question assessing continence was based on an older questionnaire and may not have the good measurement properties of contemporary questionnaires, and that BMI was by self-report.

For analysis purposes we opted to use “any incontinence” in terms of frequency of the symptom, although we noted about 60% of those with incontinence had this symptom monthly or more often and 15% had daily or more often incontinence. We felt the volume of incontinence question was, by contemporary standards, likely to be inaccurate as a gauge of incontinence severity.[7]

The prevalence identified in this survey is likely to be relatively unbiased because of the robust sampling process, the relatively high response rate and using questions about frequency of incontinence that were likely to elicit a response close to the target response of “any incontinence.” Prevalence of urinary incontinence identified in

Table 1: Urinary incontinence prevalence by age band and BMI category.

All	Raw proportion N/N (%)	Proportion (%) adjusted for sampling weights (95% confidence interval)
Age band (years)		
16–29	340/1,304 (26.1)	20.8 (18.1–23.6)
30–49	1,013/2,200 (46.1)	46.6 (43.7–49.4)
50–74	1,119/2,181 (51.3)	51.0 (48.3–53.8)
BMI categories		
<18.5	15/80 (18.8)	13.2 (5.8–20.6)
18.5–25	582/1,688 (34.5)	33.2 (31.3–36.2)
25–30	651/1,503 (43.3)	42.0 (38.7–45.3)
>30	1,088/2,106 (51.7)	51.6 (48.7–54.6)
BMI categories		
<18.5		
Age band (years)		
16–29	1/36 (2.8)	0.9 (0–2.8)
30–49	7/24 (29.2)	32.5 (10.0–55.0)
50–74	7/13 (35.0)	23.1 (4.1–42.1)
18.5–25		
Age band (years)		
16–29	102/470 (21.7)	17.1 (12.9–21.4)
30–49	254/665 (38.2)	39.5 (34.6–444)
50–74	226/533 (40.9)	42.3 (36.9–47.7)
25–30		
Age band (years)		
16–29	68/283 (24.0)	20.7 (14.8–26.6)
30–49	265/563 (47.1)	46.7 (41.2–52.2)
50–74	318/657 (48.4)	48.6 (43.5–53.6)
>30		
Age band (years)		
16–29	125/400 (31.3)	27.0 (21.7–32.4)
30–49	425/811 (52.4)	54.0 (49.2–58.88)
50–74	538/895 (60.1)	60.3 (56.0–64.6)

Table 2: Urinary incontinence prevalence by age band and parity.

All	Raw proportion N/N (%)	Proportion (%) adjusted for sampling weights (95% confidence interval)
Age band (years)		
16–29	340/1,304 (26.1)	20.8 (18.1–23.6)
30–49	1,013/2,200 (46.1)	46.6 (43.7–49.4)
50–74	1,119/2,181 (51.3)	51.0 (48.3–53.8)
Parity		
0	82/230 (35.7)	33.7 (26.2–41.3)
1	392/876 (44.8)	43.7 (39.2–48.2)
2	747/1,465 (51.3)	52.0 (48.6–55.4)
3+	876/1,643 (53.3)	55.2 (52.0–58.5)
Parity categories		
0		
Age band (years)		
16–29	29/91 (31.9)	34.2 (22.0–46.4)
30–49	29/91 (31.9)	25.8 (15.2–6.4)
50–74	24/48 (50)	52.1 (34.8–69.3)
1		
Age band (years)		
16–29	105/251 (41.8)	40.9 (33.0–48.8)
30–49	182/412 (44.2)	43.9 (37.3–50.6)
50–74	105/213 (49.3)	45.7 (36.5–54.9)
2		
Age band (years)		
16–29	61/135 (45.2)	41.3 (30.4–52.1)
30–49	329/643 (51.2)	52.9 (47.9–58.0)
50–74	357/678 (52.7)	52.4 (47.5–57.4)
3+		
Age band (years)		
16–29	41/117 (35.0)	38.1 (25.6–50.5)
30–49	348/634 (54.9)	56.3 (51.0–61.5)
50–74	487/892 (54.6)	55.8 (51.5–60.1)

Table 3: Urinary incontinence prevalence by parity and BMI category.

All	Raw proportion N/N (%)	Proportion (%) adjusted for sampling weights (95% confidence interval)
BMI category		
<18.5	15/80 (18.8)	13.2 (5.8–20.6)
18.5–25	582/1,688 (34.5)	33.2 (31.3–36.2)
25–30	651/1,503 (43.3)	42.0 (38.7–45.3)
>30	1,088/2,106 (51.7)	51.6 (48.7–54.6)
Parity		
0	82/230 (35.7)	33.7 (26.2–41.3)
1	392/876 (44.8)	43.7 (39.2–48.2)
2	747/1,465 (51.3)	52.0 (48.6–55.4)
3+	876/1,643 (53.3)	55.2 (52.0–58.5)
Parity categories		
0		
BMI category		
<18.5	0/2 (0)	NA
18.5–25	17/70 (24.3)	23.9 (11.1–36.6)
25–30	19/48 (36.6)	40.0 (22.6–57.3)
>30	31/73 (42.5)	36.3 (23.0–49.5)
1		
BMI category		
<18.5	2/8 (25)	18.2 (0–45.0)
18.5–25	111/292 (38.0)	38.7 (31.0–46.4)
25–30	104/225 (46.2)	46.3 (37.2–55.3)
>30	144/286 (50.4)	51.1 (43.3–58.8)
2		
BMI category		
<18.5	9/20 (45)	34.1 (10.2–58.0)
18.5–25	215/442 (48.6)	47.7 (41.8–53.5)
25–30	199/427 (46.6)	45.5 (39.4–51.5)

Table 3 (continued): Urinary incontinence prevalence by parity and BMI category.

>30	291/498 (58.4)	62.8 (57.1–68.4)
3+		
BMI category		
<18.5	2/10 (20)	38.0 (0–78.0)
18.5–25	143/36 (39.1)	44.9 (37.9–52.0)
25–30	244/461(52.9)	55.2 (49.2–61.1)
>30	450/737 (61.1)	60.7 (55.9–65.5)

Table 4: Association between urinary incontinence and age band, BMI category and parity.

Comparison	Odds ratio (95% confidence interval)	P-value
Age band–parity interaction	NA	0.14
Age band–BMI category interaction	NA	0.49
Age band (years) main effect		0.04
30–49 versus 16–29	1.5 (1.1–1.9)	
50–74 versus 16–29	1.5 (1.1–2.0)	
Parity–BMI category interaction		<0.001
Parity 0		
<18.5 versus 18.5–25	NA	
25–30 versus 18.5–25	2.2 (0.8–6.1)	
>30 versus 18.5–25	1.9 (0.8–4.8)	
Parity 1		
<18.5 versus 18.5–25	0.4 (0.06–2.3)	
25–30 versus 18.5–25	1.3 (0.8–2.2)	
>30 versus 18.5–25	1.7 (1.1–2.7)	
Parity 2		
<18.5 versus 18.5–25	0.6 (0.2–1.7)	
25–30 versus 18.5–25	0.9 (0.7–1.3)	
>30 versus 18.5–25	1.7 (1.1–2.7)	
Parity 3+		
<18.5 versus 18.5–25	0.8 (0.1–4.3)	
25–30 versus 18.5–25	1.5 (1.0–2.2)	
>30 versus 18.5–25	1.9 (1.3–2.7)	

Table 5: Urinary incontinence prevalence by age band and ethnicity.

All	**Raw proportion** **N/N (%)**	**Proportion (%) adjusted for sampling weights** **(95% confidence interval)**
Age band (years)		
16–29	340/1,304 (26.1)	20.8 (18.1–23.6)
30–49	1,013/2,200 (46.1)	46.6 (43.7–49.4)
50–74	1,119/2,181 (51.3)	51.0 (48.3–53.8)
Total	2,472/5,685 (43.5)	41.7 (40.0–43.4)
Ethnicity categories		
Non-Māori		
Age band (years)		
16–29	198/867 (22.8)	18.9 (15.8–22.0)
30–49	716/1,612 (44.4)	45.9 (42.7–49.0)
50–74	865/1,733 (49.9)	50.3 (47.3–53.4)
Total	1,779/4,212 (42.2)	41.2 (39.3–43.1)
Māori		
Age-band (years)		
16–29	142/497 (32.5)	29.2 (23.9–34.6)
30–49	297/588 (50.5)	51.1 (45.7–56.4)
50–74	254/448 (56.7)	57.5 (51.7–63.3)
Total	693/1,473 (47.1)	45.0 (41.7–48.3)
Non-Pacific		
Age band (years)		
16–29	299/1,153 (25.9)	20.8 (17.9–23.8)
30–49	951/2,051 (46.4)	46.8 (43.9–49.7)
50–74	1,097/2,125 (51.6)	51.7 (48.9–54.5)
Total	2,347/5,329 (44.0)	42.5 (40.7–44.3)
Pacific		
Age band (years)		
16–29	41/151 (27.2)	21.0 (13.4–28.6)
30–49	62/149 (41.6)	43.0 (33.0–53.1)

Table 5 (continued): Urinary incontinence prevalence by age band and ethnicity.

50–74	22/56 (39.3)	25.0 (13.1–36.9)
Total	125/356 (35.1)	29.6 (23.8–35.3)
Non-Asian		
Age band (years)		
16–29	327/1,145 (28.6)	24.7 (21.5–28.0)
30–49	952/2,000 (47.6)	48.6 (45.6–51.6)
50–74	1,096/2,106 (52.0)	51.8 (48.9–54.6)
Total	2,375/5,251 (45.2)	44.4 (42.5–46.2)
Asian		
Age band (years)		
16–29	13/159 (8.2)	5.3 (2.1–8.5)
30–49	61/200 (30.5)	34.1 (25.8–42.4)
50–74	23/75 (30.7)	36.9 (22.2–51.6)
Total	97/434 (22.4)	22.8 (17.6–27.4)
Non-European		
Age band (years)		
16–29	118/516 (22.9)	14.9 (11.4–18.5)
30–49	271/636 (42.6)	41.0 (35.6–46.3)
50–74	207/387 (53.5)	47.2 (39.9–54.5)
Total	596/1,539 (38.7)	31.9 (28.7–35.1)
European		
Age band (years)		
16–29	222/788 (28.2)	24.4 (20.6–28.2)
30–49	742/1,564 (47.4)	48.5 (45.2–51.9)
50–74	912/1,794 (50.8)	51.6 (48.6–54.6)
Total	1,876/4,146 (45.2)	44.8 (42.8–46.8)

Table 6: Association between urinary incontinence and ethnicity in adjusted models.

Comparison	Odds ratio (95% confidence interval)	P-value
Māori ethnicity		
Age band (years)		0.02
30–49 versus 16–29	1.5 (1.1–2.0)	
50–74 versus 16–29	1.5 (1.1–2.0)	
BMI category		<0.001
<18.5 versus 18.5–25	0.6 (0.3–1.3)	
25–30 versus 18.5–25	1.2 (1.0–1.5)	
30+ versus 18.5–24	1.8 (1.5–2.3)	
Parity		0.002
1 versus 0	1.6 (1.1–2.5)	
2 versus 0	2.0 (1.3–3.1)	
3+ versus 0	2.1 (1.4–3.2)	
Māori versus non-Māori	1.0 (0.8–1.2)	0.85
European ethnicity		
Age band (years)		0.03
30–49 versus 16–29	1.5 (1.1–1.9)	
50–74 versus 16–29	1.4 (1.1–2.9)	
BMI category		<0.001
<18.5 versus 18.5–25	0.6 (0.3–1.3)	
25–30 versus 18.5–25	1.2 (1.0–1.5)	
30+ versus 18.5–24	1.8 (1.5–2.3)	
Parity		0.001
1 versus 0	1.7 (1.1–2.6)	
2 versus 0	2.0 (1.3–3.1)	
3+ versus 0	2.2 (1.4–3.3)	
European versus non-European	1.2 (1.0–1.5)	0.09

Figure 1: Urinary incontinence prevalence by age, BMI and parity.

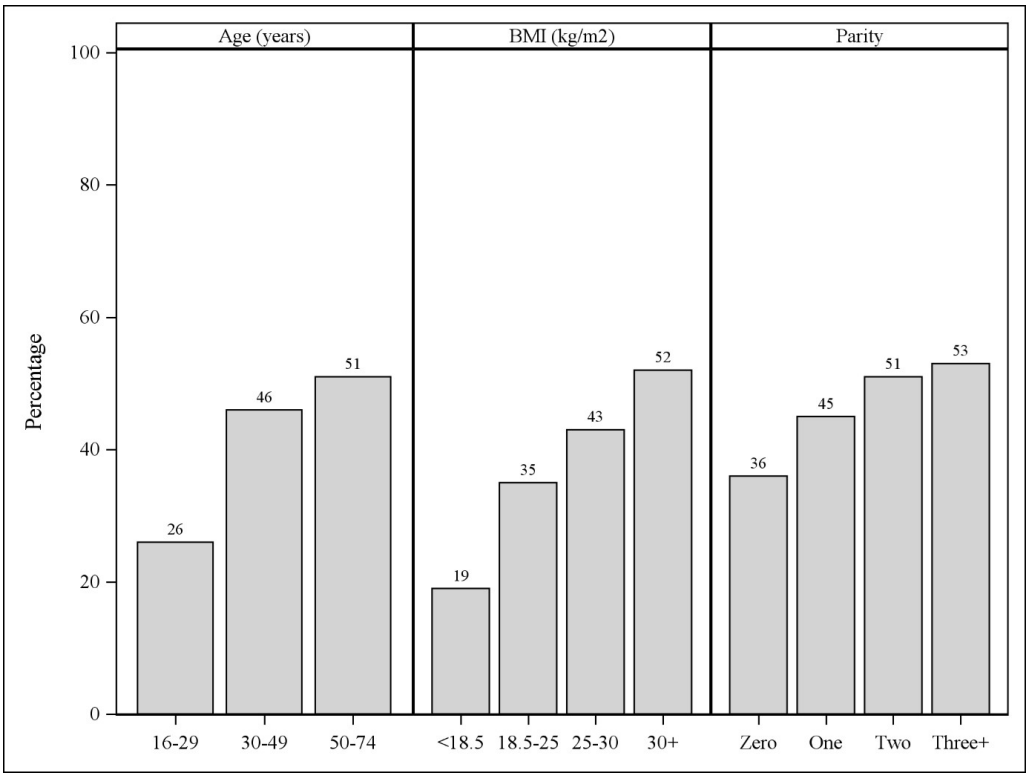
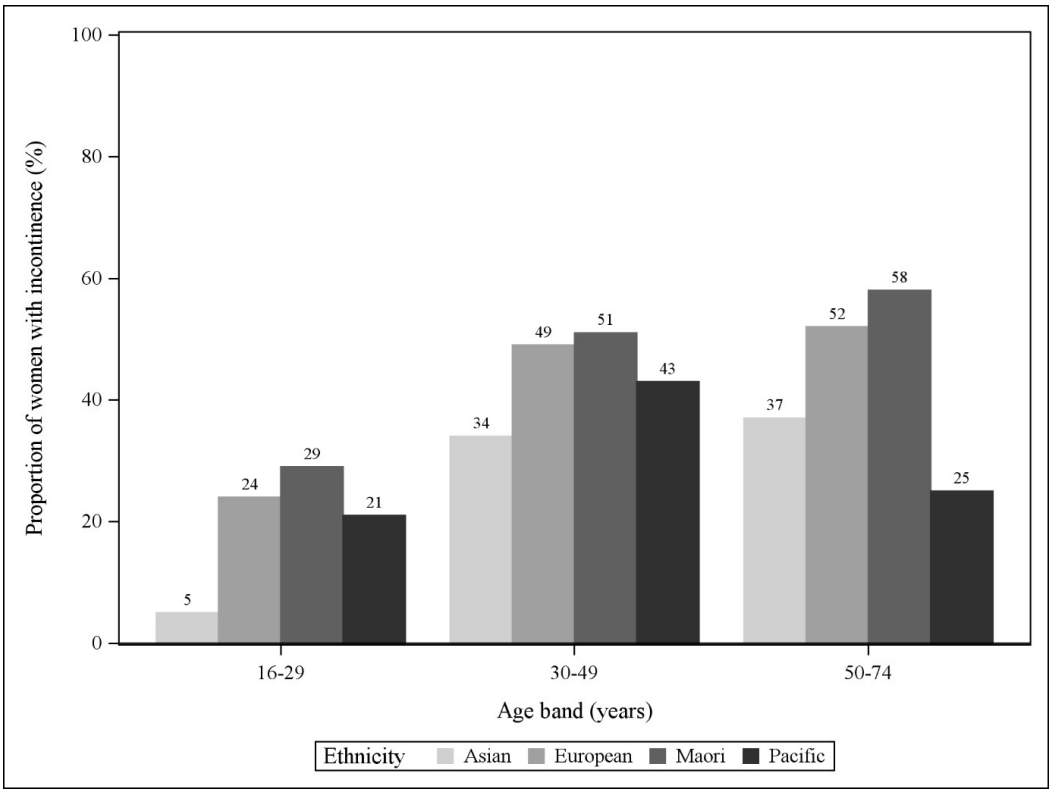


Figure 2: Urinary incontinence prevalence by ethnicity and age band.



the Health Survey is substantially higher than that in other New Zealand surveys. It is difficult to know how much response bias and sample frame inefficiencies (such as relying only on the electoral roll) may have caused this discrepancy, or whether this represents an increase in the prevalence of a likely causal risk factor—obesity—for the respondents in this survey compared to past surveys.

This Health Survey did not ask about help-seeking behaviour or about self-management strategies, but clearly there is likely to be substantial unmet need both for treatment and for provision of healthcare management to otherwise reduce the effect of incontinence on quality of life as well as an additional problem of inequitable distribution of services across New Zealand.[8] It would be useful for healthcare planners to consider addressing the unmet needs of women with incontinence, as it seems likely most women are not seeking help and are funding their own continence care, such as self-purchase of continence products. This has been the case in the United Kingdom,[9] although the New Zealand Women's Health Strategy only mentions incontinence twice, and one of these in relation to the issue of surgical mesh.[10] It would be useful to compare the New Zealand approach to the provision of "period" products with the difficulty of access to continence services and products.

For older adults with continence problems there is non-experimental evidence in New Zealand that continence, particularly in the setting of mobility problems, is associated with an increased risk of residential care.[11,12] If the very high prevalence of incontinence in this group, up to age 75, is carried through to older age, this may be challenging for healthcare resources allocated to the care of older adults.

We were unable to identify a difference in the prevalence of incontinence in relation to ethnicity after adjustment for age, parity and body size as measured by self-reported BMI. There may still be inequities in relation to continence, however, in relation to access to healthcare or continence products where these are needed. This was not captured in the Health Survey.

The associations with urinary incontinence identified in the Health Survey have been previously reported for all of age, obesity and parity.[13–19] Of these, likely the factor that may be most amenable to change may be obesity: both at an individual level for those with incontinence and a larger body size, but also at population level.

COMPETING INTERESTS
Nil.

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Modern paradigms in biologic sequencing of inflammatory bowel disease in Aotearoa New Zealand

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ABSTRACT

The modern treatment of inflammatory bowel disease (IBD) has evolved significantly in recent years. This includes development of new pharmacologic therapies and their implementation in clinical practice. Moderate-to-severe IBD represents a group of patients at risk of poorer outcomes, and mounting evidence suggests biologic and small molecule medications, collectively termed advanced therapies, are the most effective tools clinicians possess.

Even with biologic treatment, many patients do not respond or lose response over time. Until recently, most randomised trials demonstrating efficacy and safety of biologics have been placebo-controlled with a lack of head-to-head studies. Therefore, selecting the right medication for the appropriate clinical scenario can be difficult. In addition, there is evidence of differing clinical success when positioning biologic treatments in different sequences. This is important, as one-third of patients treated with biologics will require a switch to a second agent by 12 months, and a further 20% will require a third agent.

Over the years, there have been widespread calls in Aotearoa New Zealand for increasing biologic treatment options. Ustekinumab and vedolizumab received public funding for the treatment of moderate-to-severe IBD in 2023, and this has presented long-awaited opportunities for patients, but also new challenges for clinicians in regard to treatment selection. The purpose of this document is to provide guidance to clinicians on biologic selection, sequencing and optimisation for IBD. These recommendations are specific to the domestic prescribing climate, supported by the best available evidence and endorsed by the New Zealand Society of Gastroenterology IBD Working Group.

The modern treatment of inflammatory bowel disease (IBD) has evolved significantly in recent years. This includes development of new pharmacologic therapies for disease control, and their implementation in clinical practice. Moderate-to-severe IBD represents a group of patients at risk of poorer outcomes. Mounting evidence suggests biologic and small molecule medications, collectively termed advanced therapies, are the most effective tools clinicians possess, and many societal guidelines recommend their early deployment to achieve best outcomes.[1–4]

Even with biologic treatment, many patients do not respond or lose response over time, termed primary non-response (PNR) and loss of response (LOR), respectively.[5,6] Until recently, most randomised trials demonstrating efficacy and safety of biologics have been placebo-controlled, with a lack of head-to-head studies and active comparators.[7] Therefore, selecting the right medication for the appropriate clinical scenario can be difficult, and is not guided by high-quality prospective comparative data. In addition, there is emerging evidence of differing clinical success when positioning biologic treatments in different sequences.[8–11] This is important, as one-third of patients treated with biologics will require a switch to a second agent by 12 months, and a further 20% will require a third agent.[12] The optimal sequence to treat patients is currently supported by network meta-analyses, real-world studies and expert opinion.[13]

Over the years, there have been widespread calls in Aotearoa New Zealand (New Zealand) for increasing biologic treatment options for IBD beyond anti-tumour necrosis factor alpha inhibitors (anti-TNFs). Ustekinumab (UST) and vedolizumab (VDZ) received public funding for the treatment of moderate-to-severe IBD in February 2023, and this has presented long-awaited opportunities for IBD patients, but also new challenges for clinicians in regard to treatment selection. There is significant regional variation in expertise across New Zealand, and in some centres, general physicians and surgeons manage IBD rather than specialist gastroenterologists.[14] The purpose of this document is to provide guidance to clinicians on biologic selection and sequencing

in patients with moderate-to-severe disease. These recommendations are specific to the New Zealand prescribing climate, supported by the best available evidence, and endorsed by the New Zealand Society of Gastroenterology IBD Working Group through consensus voting.

Individualising biologic treatment selection

In adult patients with IBD, medication selection may be informed by patient, disease, drug and/or systemic factors. The relevant patient factors include age, comorbidities, preferences and impact on whānau and lifestyle—each requiring balanced consideration. Secondly, disease behaviour, such as presence of fistulising disease, inflammatory burden and/or extra-intestinal manifestations may influence treatment selection. Thirdly, drug factors must be considered, such as speed of onset, efficacy, safety, adverse effects, mode of administration and risks of immunogenicity, the latter specifically influencing immunomodulator (IM) co-prescription. Responsible prescribing means clinicians also need to understand system factors, such as costs of medicines, demands on infusion centres and local drug availability.

New Zealand continues to have restricted access to biologics, including to biosimilars beyond Amgevita (adalimumab). Biosimilar therapies are manufactured medications that have virtually indistinguishable properties to their originators but offered at significant cost discounts.[15] PHARMAC is the national drug-purchasing agency, which has governance over special authority criteria designed to minimise healthcare expenditure. Understanding these criteria is fundamental to prescribing in New Zealand.[16] While allocation of limited healthcare resource is important, medication costs also need to be balanced against costs of persisting disease activity and healthcare utilisation from sub-optimally treated patients.[17] It is notable, for example, that small molecule advanced therapeutics are not currently funded in New Zealand.

Moderate-to-severe ulcerative colitis

The therapeutic approach to moderate-to-severe ulcerative colitis (UC) has evolved to favour advanced therapies, as these patients have a more aggressive disease course and higher likelihood of requiring hospitalisation or colectomy. This is reflected in international guidelines such as those published by the American Gastroenterological Association recommending early use of biologic agents over step-up treatment.[3] Biologics have advantages over alternatives in terms of superior efficacy, more rapid effect onset and flexibility with individualised dose optimisation.[18–20] These guidelines define moderate-to-severe UC as a Mayo score of 6 or above with endoscopic sub-score of 2 or above, and/or patients who are dependent or refractory to corticosteroid treatment.

The suggested biologic sequence for moderate-to-severe UC is summarised in Table 1. This sequence is unique to New Zealand in the context of current PHARMAC reimbursement criteria (at time of publication).

1. Biologic-naïve UC and first-line therapies

For patients with moderate-to-severe biologic-naïve UC, we recommend vedolizumab (VDZ) or infliximab (IFX) for first-line use, favouring VDZ in most cases. IFX will be most familiar to local clinicians and has faster speed of onset. It is also the only approved biologic in acute severe ulcerative colitis (ASUC). However, VDZ is safer, has superior treatment persistence data and overall may be better as a first-line choice in the majority.[21–23] Several past studies, including network meta-analyses by Singh et al. showed comparable efficacy between these agents, but due to its relative novelty, long-term data on VDZ is still emerging.[24–29]

1.1 Vedolizumab (VDZ)

Vedolizumab (VDZ) is an IgG1 monoclonal antibody that binds to the α4β7 integrin on T cells. This integrin mediates lymphocyte migration within gut mucosa and its blockade produces a gut-selective, anti-inflammatory effect.[30] The advantage of this mechanism of action is in the preservation of normal systemic immunity.[30] VDZ is therefore an attractive option in patients at risk of immunosuppressive (IS) adverse events, including elderly populations and those with comorbidities.[31] The favourable safety of VDZ was published in the landmark GEMINI randomised trials, which demonstrated comparable adverse events to placebo.[32]

There are no prospective, head-to-head, randomised controlled trials comparing VDZ and IFX in UC, but there are a few high-quality retrospective and real-world studies to draw conclusions from. In a large United Kingdom (UK) cohort study, 13,222 patients with biologic-naïve

UC treated with VDZ were compared with IFX and 5-year drug effectiveness was superior for VDZ (p=0.006).[23] Likewise, in the $VEDO_{IBD}$ registry, 512 patients in multiple centres across Germany had superior long-term clinical remission when initially treated with VDZ versus anti-TNF (43.2% VDZ vs 25.8% anti-TNF, p<0.011).[21] A large American database study also found higher treatment persistence with VDZ at both 12 months (84.5% VDZ vs 77.5% IFX) and 24 months (77.6% VDZ vs 64.6% IFX).[33]

VDZ has a relatively long half-life of up to 26 days, which means it may take 3 months before reaching steady state concentrations and maximal therapeutic effect.[34] Initial response can be seen within 2 weeks, but concurrent induction with corticosteroids may need to be considered.[35,36] VDZ can be dose intensified and given every 4 weeks in the setting of LOR.[37] This is not currently funded in New Zealand, but can be obtained via application for compassionate supply from the manufacturer.

In regard to immunogenicity, anti-drug antibodies (ADAbs) are rare and occur in around 4% of patients treated with VDZ.[38] Concomitant IMs may only reduce this risk by a small margin and therefore VDZ is recommended as monotherapy, especially when being used first-line.[39] In select patients with severe disease already established on IMs, we recommend review of combination therapy on a case-by-case basis. Overall, with respect to safety, rates of long-term remission, treatment persistence and advantages of monotherapy, VDZ is ideally positioned as a first-choice option for biologic-naïve UC.

1.2 Infliximab (IFX)

Infliximab (IFX) is a chimeric anti-TNF that blocks the interaction between TNFα and its receptor. This prevents activation of multiple downstream inflammatory cascades with a rapid onset of action.[40] This rapidity makes IFX particularly useful as a steroid-sparing agent for induction of remission.[40] In the meta-analysis by Trigo-Vicente et al., IFX demonstrated greater efficacy with induction compared with VDZ (OR: IFX 4.15 vs VDZ 3.7).[26]

IFX should be prioritised as first-line therapy when a rapid response is required or where there is significant extra-intestinal disease. Currently, IFX is the only biologic approved for use in ASUC.[41] In patients with extra-intestinal manifestations (EIM), particularly arthropathies, ocular manifestations and IBD-related skin disease, the anti-TNF therapies carry the most evidence and are most efficacious.[42,43]

As IFX contains a murine (mouse-derived) drug component, it is more immunogenic than other biologics and therefore immunomodulator co-prescription is generally recommended to preserve drug levels, especially during the first year of therapy.[44] In the setting of low drug titres, dose escalation or shortening of the dosing interval is warranted, although this is limited in New Zealand under current funding models.[45] A meta-analysis of 41 included studies showed that 5–50% of all induced patients required dose escalation, and 15–70% of initial responders required subsequent dose escalation within the first year.[46] Furthermore, longitudinal studies have shown that rates of required dose escalation probably increase with time.[47] Subcutaneous (SC) biosimilar IFX is not currently available in New Zealand, but has advantages of a more stable pharmacokinetic profile and reduced rates of ADAbs.[48] Variation in access to infusion centres across New Zealand may also make SC delivery more equitable. The availability of SC biosimilar IFX may alter the sequencing landscape when approved.

1.3 Adalimumab (ADA)

Adalimumab (ADA) is a recombinant human anti-TNF that is administered subcutaneously. While this is convenient for administration, it is not as effective as VDZ or IFX for biologic-naïve UC.[49,50] The VARSITY trial is one of a few randomised head-to-head trials comparing efficacy of VDZ with ADA.[50] In the sub-group analysis of biologic-naïve patients, ADA showed inferior rates of clinical remission, mucosal healing and histologic remission after 1 year.[50] ADA was also inferior to IFX at reducing hospitalisation in a nationwide, propensity-matched study from Denmark.[49]

One of the reasons that ADA might be selected in UC is patient preference for self-administered SC injection over IV infusion in terms of lifestyle and avoiding time at infusion centres.[51] Dose intensification to weekly administration should be considered following LOR and is reimbursed through PHARMAC.

The only biosimilar currently available in New Zealand is Amgevita, which has largely replaced Humira, the originator ADA biologic. Biosimilars have significant healthcare cost advantages, so for patients with milder UC phenotypes, in spite of its lower efficacy, Amgevita might be considered as an alternative first-line agent, prioritising

patient preference and healthcare savings.[52] This recommendation will likely change with introduction of the aforementioned SC IFX biosimilars and/or SC VDZ.

1.4 Ustekinumab (UST)

Ustekinumab (UST) is currently reserved for biologic-exposed patients under New Zealand special authority criteria. UST is an IgG1 monoclonal antibody that antagonises interleukin-12 and interleukin-23. These cytokines share a p40 subunit which, when blocked, inhibits natural killer (NK) cell and T cell mediated inflammation.[53] Following IV induction, UST is given as a SC maintenance therapy, making it the only other SC agent available. Immunogenicity is rare, with reported rates of 2.9% in CD and 4.6% in UC after 1 year.[54,55] Concomitant IMs do not appear to modify this risk or improve efficacy; therefore, cessation of IMs should be considered in most patients.[56]

2. Biologic-exposed UC and sequencing

2.1 Dose optimisation and therapeutic drug monitoring (TDM)

Dose optimisation and countering immunogenicity should be considered prior to switch of biologic therapy. In the modern era, this is increasingly guided by therapeutic drug monitoring (TDM), with evidence to support a TDM strategy being most robust for the anti-TNF biologics. This is especially true for IFX, where there is a clear correlation between drug trough levels and clinical efficacy.[57] PNR or LOR should prompt an assessment of treatment adherence, and measurements of drug concentrations and anti-drug antibodies. This can guide decisions regarding dose escalation, addition of concomitant therapy and switching *within-* or *out-of-* biologic class.[58,59] The evidence for dose optimisation of UST and VDZ based on TDM remains at a nascent stage.[60]

While there are no prospective studies validating a proactive TDM approach, these concepts are relevant given the limited landscape of treatments within New Zealand and diminishing effectiveness with sequential lines of therapy.[61]

2.2 Non-response to biologics

Non-response to VDZ—switch to IFX or UST

In the setting of non-response to VDZ, we recommend switching to either IFX or UST as second-line agents. Neither of these have been shown to have reduced efficacy following anti-integrin (VDZ) use and, in fact, there might be higher activation of TNF signalling in VDZ non-responders.[62] This further supports the early positioning of VDZ in the sequence of biologic treatments for UC, in order to preserve subsequent biologic choices.[61]

Non-response to anti-TNFs—switch to UST

In patients who do not respond to first-line anti-TNFs, we recommend a switch to UST as the best sequencing option. Multiple studies have shown that prior anti-TNF exposure can negatively impact likelihood of subsequent response to a second-line biologic agent. This is true of VDZ, ADA and ozanimod, which were studied in GEMINI, VARSITY/ULTRA II and True North respectively.[50,63,64] It has been theorised that non-responders to anti-TNFs may upregulate IL-23 that becomes resistant to apoptosis, so blockade of these receptors forms the mechanistic theory of preserved UST effect.[65,66]

In the UNIFI trial, UST was compared with placebo for both biologic-naïve and biologic-exposed patients, with the majority of the latter group having previously been treated with anti-TNFs. On sub-group analysis, rates of remission between biologic-naïve and exposed groups were comparable, with only minimal differences in clinical response and mucosal healing.[53] TORUS is a recently published multi-centre, real-world study that sought to corroborate these findings. The authors highlighted some negative exposure effects, particularly in the setting of more than one prior biologic failure (OR, 2.88; 95% CI, 1.20–6.98); however, the magnitude of difference was less for UST than other cited studies involving different biologics.[67] Dose intensified UST is not currently funded in New Zealand but can be obtained for off-label use via application for compassionate supply from the manufacturer.

With VDZ use in biologic-exposed patients, the prior exposure effects are more pronounced. A clinical response of 53.1% was demonstrated in anti-TNF-naive patients versus 39.0% in anti-TNF-exposed patients. There were also significantly worse outcomes in rates of clinical remission (23.1% vs 9.8%) and mucosal healing (49.2% vs 30.5%).[68]

In any case, non-response to anti-TNF therapy should be considered a predictor of treatment-resistant disease, with these patients significantly less likely to respond to a second-line biologic. A systematic review and meta-analysis of IBD patients who stopped their anti-TNF due to PNR demonstrated a 24% lower likelihood of achieving remission with another biologic compared with those who stopped due to intolerance (RR of remission—0.76 [0.61–0.96]).[5]

3. Third-line biologics for UC and beyond

When attempting to recapture remission with third-line biologics, consideration needs to be made for the overall trajectory of the patient and the predicted likelihood of success with additional conventional therapies. As mentioned, there is negatively correlated clinical efficacy with increasing numbers of biologic exposures, so alternative approaches should be considered.

3.1 Clinical trials

Clinical trials are a fundamental component of the modern treatment armamentarium, as they allow patients' access to novel therapies. Most current biologic trials are designed with several active treatment arms, as well as continued access through long-term extensions. Clinical trials should be considered for all suitable IBD patients to widen therapeutic access, especially in those with moderate-to-severe disease. There are initiatives within Health New Zealand – Te Whatu Ora that aim to improve regional access to clinical trials and better coordinate IBD care. Centres without specific trial coordinators should be aware which sites have access and refer appropriately.

3.2 Janus Kinase (JAK) inhibitors

JAK inhibitors are small molecules that block tyrosine kinases, responsible for intra-cellular transmission of inflammatory signals.[69] Within T cells, JAK-STAT signalling triggers differentiation into T helper cells, which have a key role in mediating the inflammatory response in IBD.[70] The landmark OCTAVE trials demonstrated clinical efficacy of JAK inhibitors in both biologic-naïve and biologic-experienced patients, and this has been confirmed with large, real-world systemic reviews/meta-analyses.[71,72]

Differing from the monoclonal antibody biologics, these small molecules are administered orally, have a rapid onset of action, are non-immunogenic and also non-specific in their effect, therefore carrying the potential to block multiple inflammatory pathways simultaneously.[73] The rapid onset of action and high bioavailability have led to their consideration as an adjunctive treatment in ASUC.[74,75]

These are not currently funded in New Zealand for IBD but are being considered by authorities and will be highly ranked in treatment algorithms once approved. These will be especially valuable treatments for biologic-experienced patients once available.

3.3 Colectomy

Colectomy should be considered in biologic-refractory patients, especially those approaching third-line biologics. In patients who have exhausted IFX and UST, this needs to be strongly considered due to the aforementioned attenuated effect of ADA and VDZ in the biologic-experienced cohort. Surgery offers a cure for UC and obviates the need for maintenance therapies and surveillance of dysplasia. We recommend early involvement of a colorectal surgeon and multi-disciplinary discussion alongside patients in this setting.

Moderate-to-severe Crohn's disease

Crohn's disease (CD) is a chronic inflammatory disease which, unlike UC, has no surgical cure in treatment-refractory cases. Complications of CD can be severe, including intestinal stricturing, obstruction, fistulae, abscesses, hospitalisation and surgery.[76] Tight disease control is therefore mandatory to prevent morbidity. This involves regular clinical assessment and early escalation to biologic therapy, especially in moderate-to-severe disease and those with phenotypic risk factors including deep ulceration, strictures, extensive or fistulising disease.

There are drawbacks to using symptom-based scoring systems in CD, where clinical presentations may be heterogeneous, and morbidity may arise from untreated sub-clinical disease. Modern paradigms in disease assessment preference composite metrics of disease activity, including measurement of biomarkers, and we suggest this approach when determining best treatment strategies.[77] These guidelines define moderate-to-severe luminal CD as patients with a CD activity index of 220 or above, those who are dependent or refractory to corticosteroid treatment, or those with phenotypic risk factors, such as large or deep mucosal lesions on endoscopy.

The suggested biologic sequence for CD is summarised in Table 2. This sequence is unique to New Zealand in the context of current PHARMAC reimbursement criteria (at time of publication).

1. Biologic-naïve CD and first-line therapies

Luminal CD

As with UC, biologic selection should be personalised based on disease characteristics, patient factors and preferences, as well as access and systemic factors. In biologic-naïve luminal

CD, anti-TNF agents are generally the preferred first-line choice.

1.1 Anti-TNF therapy (ADA or IFX)

Multiple studies support use of both ADA or IFX in induction and maintenance settings.[78,79] There is currently no head-to-head data comparing these two choices and real-world studies provide conflicting evidence. Some meta-analyses suggest comparable efficacy, whereas others demonstrate slight superiority of IFX.[23] This difference may be adjusted when considering combination therapy with IMs. For example, on the basis of 15 randomised controlled trials and 2,931 enrolled patients, different biologics were compared with certolizumab pegol in a meta-analysis. IFX plus azathioprine (OR 7·49 [2·04–27·49]) and IFX monotherapy (OR 4·53 [95% CI 1·49–13·79]) were both superior to ADA monotherapy (OR 3·01 [1·25–7·27]) and ustekinumab monotherapy (OR 2·63 [1·10–6·28]).[4]

In the absence of robust head-to-head data, either anti-TNF selection is appropriate first-line. ADA carries the advantages of self-administration and cost savings, whereas IFX has the advantage of greater capability with dose escalation, which can be attractive in difficult-to-treat disease. IM co-prescription should be considered to prevent ADAbs, with IFX being particularly immunogenic.

1.2 Vedolizumab (VDZ)

VDZ may not be as efficacious as the anti-TNF agents for luminal CD with lower surface under the cumulative ranking (SUCRA) probabilities in network meta-analyses.[80] However, there is development of a validated clinical decision support tool (CDST) to predict which patients may be more likely to respond to VDZ treatment.[81] These tools are not yet routinely utilised in clinical practice, but may help select patient profiles appropriate for first-line VDZ. At this stage, VDZ would be considered a first-line alternative in those with a milder disease phenotype or in the co-morbid patient, especially due to its safety advantages.

1.3 Ustekinumab (UST)

In New Zealand, UST is reserved for biologic-exposed patients under special authority criteria. However, there is mounting evidence to support its use in the biologic-naïve setting, and this is a trend observed internationally due to its efficacy, subcutaneous administration, lack of immunogenicity and superior treatment persistence. The SEAVUE study was a multi-centre, randomised, double-blind, active comparator trial in biologic-naïve patients with CD. This showed no significant difference in efficacy between ADA (61%) and UST (65%) in remission rates at 12 months.[82] This is supported by 10-year national data from South Korea showing superior treatment persistence with UST compared to IFX (adjusted hazard ratio [aHR] 0.69, p=0.048).[83] While UST would be an attractive first-line treatment for luminal CD, this is not currently funded.

2. Fistulising CD

Infliximab

The majority of fistulising CD involves perianal fistula, which can occur in up to one-third of CD patients.[84] Luminal fistulising CD is also observed, which can form between one loop of bowel and another (enteroenteric), from bowel to bladder (enterovesicular), vagina (enterovaginal) or skin (enterocutaneous), posing a substantial burden on physical, social and emotional wellbeing. The presence of fistulising perianal or luminal disease establishes a severe phenotype that signals the need for biologic treatment. It is noteworthy that fistulising CD is one of the only indications in New Zealand where anti-TNF therapies are funded regardless of symptoms and previous treatment exposure.

The majority of published studies on drug therapies in fistulising CD apply to outcomes for perianal disease, with more limited data on luminal fistulae. Recommendations from this guideline have been made based on best available evidence for perianal CD, with the extrapolation that a similar response to therapy is likely observed in other forms of fistulae.

Anti-TNFs are the preferred treatment in this setting, with IFX the only evidence-based biologic. This was demonstrated in a large, dedicated, randomised, placebo-controlled trial that showed a 69% response rate following induction, with sustained results at 1 year (IFX 46% vs placebo 23%, p=0.001).[85] While there is some data supporting the use of ADA, VDZ and UST in fistulising disease, the evidence is less robust, and IFX should be considered first-line, especially for complex fistulae.[86]

Surgical management is outside the scope of this article, however there is evidence for improved outcomes with combined surgical and medical management in complex fistulising CD.

3. Biologic-exposed CD and sequencing

3.1 Non-response to anti-TNF—switch to UST

Primary non-response to an anti-TNF agent

occurs in up to 24% of CD patients within 3 months of commencing treatment.[87] Various factors including disease duration, disease phenotype, body mass index (BMI), prior surgery and smoking status have been implicated.[88] In this setting, sequential use of another anti-TNF is fraught, with a recaptured remission rate of only 30%. This is compared with over 60% when the reason for switching medication is intolerance.[89]

Therefore, in PNR we recommend switching *out-of-class* to UST. Similar to UC, UST efficacy in CD is not affected by prior anti-TNF exposure, possibly due to IL-23 up-regulation.[90–92] However, the same is not true of VDZ.[93,94] Comparing real-world data, there is superior treatment persistence with second-line UST (79.2%) compared with VDZ (54.9%).[83] When deploying VDZ in bio-exposed patients, we suggest a low threshold for consideration of an additional week 10 dose via individual application for compassionate supply from the manufacturer.

3.2 Loss of response to anti-TNF—dose escalate before switch to UST

Loss of response to anti-TNF therapy is a common issue and occurs in 23–46% of CD patients, with a 13% per patient-year risk.[88] This is frequently driven by low drug levels and/or immunogenicity.[95] As discussed within the UC section, we recommend application of TDM principles and dose optimisation to attempt to recapture response as the first countermeasure. The randomised ACCENT I study showed that 90% of patients who lost response to 5mg/kg IFX restored response after an escalation in dose to 10mg/kg.[96] Furthermore, almost 80% of patients who had LOR to 10mg/kg dosing regained response after another dose escalation to 15mg/kg.[96] Reducing the interval between doses has a similar effect, with a multi-centre Spanish study demonstrating 83% of patients regaining response with 4-weekly dosing.[97] The presence of high anti-drug antibody titres is the primary caveat to this intensification approach, with a 90% specificity for subsequent treatment failure.[98]

4. Third-line biologics for CD and beyond

As with UC, there is reduced clinical efficacy with increasing number of biologic exposures, and alternative approaches, such as enrolment in clinical trials, should be considered to advance access to unfunded medications. There is very promising data overall for JAK inhibitors, especially upadacitinib (UPA), in this cohort of medication-refractory patients and regulatory approval is eagerly awaited. We support multi-disciplinary involvement of specialist nurses, gastroenterologists and surgeons in challenging cases.

Conclusions

Selecting the optimal biologic treatments through the chronic, relapsing course of IBD continues to be a challenge for clinicians and patients alike. Navigating this skilfully requires proactive disease assessments, therapeutic drug monitoring and attention towards expanding evidence surrounding biologic sequencing. This is a dynamic and rapidly evolving field, and recommendations will change both with emerging evidence as well as advances in national funding and medication access. We present an overview of the current evidence in this space, which aims to function as a practical and useful guide to clinicians caring for patients afflicted by these diseases.

Table 1: Biologic sequencing for ulcerative colitis (UC) in New Zealand.

	Preferred biologic		**Second-line**	**Third-line**
Bio-naïve UC	VDZ	IFX	ADA	
PNR to anti-TNF	UST		VDZ	
Elderly or safety concerns	VDZ	UST	Anti-TNF (IFX or ADA)	
Extra-intestinal manifestations	Anti-TNF (IFX or ADA)		UST	VDZ
ASUC	IFX			

Adalimumab = ADA; Anti-tumour necrosis factor = anti-TNF; acute severe colitis = ASUC; infliximab = IFX; primary non-response = PNR; ulcerative colitis = UC; Ustekinumab = UST; vedolizumab = VDZ.

Table 2: Biologic sequencing for Crohn's disease (CD) in New Zealand.

	Preferred biologic		**Second-line**	**Third-line**
Bio-naïve CD	ADA	IFX	VDZ	
PNR to anti-TNF	UST		VDZ	
LOR to anti-TNF	Switch anti-TNF		UST	VDZ
Elderly or safety concerns	UST		VDZ	Anti-TNF (IFX or ADA)
Extra-intestinal manifestations	Anti-TNF (IFX or ADA)		UST	VDZ
Perianal/fistulising disease	IFX		ADA	UST

Adalimumab = ADA; Anti-tumour necrosis factor = anti-TNF; Crohn's disease = CD; infliximab = IFX; loss of response = LOR; primary non-response = PNR; Ustekinumab = UST; vedolizumab = VDZ.

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Dying well in Aotearoa New Zealand for ethnic minority communities: a time for reclamation?

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ABSTRACT

Despite technological advances and a disproportionate increase in health expenditure at the end-of-life, most New Zealanders die in hospital or in aged residential care. This counters the aspirations espoused by Te Whatu Ora (Health New Zealand) for all New Zealanders "*to live well, age well and die well in their homes and communities*." Furthermore, despite reported inequities in end-of-life care experienced by ethnic minority communities (EMCs) overseas, and increasing proportions of people identifying with Asian, Middle Eastern, Latin American and African ethnicities in Aotearoa New Zealand, local data, research and policies addressing healthcare needs of EMCs at end-of-life are scant. Acknowledging this invisibility, we reflect on and discuss the current discourses on death and dying, the complex experiences at end-of-life for EMCs, including concepts of a "good death", the impact of recent existential crises (e.g., COVID-19 pandemic, climate change) on death awareness, and the global rise to reclaim dying as an important part of living. We argue for the need: a) to partner with ethnic communities to co-design culturally safe end-of-life health services, and b) to adopt a "compassionate communities" public health approach that can support people of EMCs at the end-of-life to die well.

Te Whatu Ora (Health New Zealand) has made explicit commitments to reduce inequities in healthcare and develop a people/whānau-centred, whole-of-society, population health system.[1] However, alongside clinical interventions, health technological advances and an overall rise in life expectancy (except for the most deprived populations where life expectancy has fallen), years lived without good health and poor symptom relief have increased from 8.6 years to 10 years.[2] In the last month of life, there is a disproportionate increase in health expenditure and acute hospital admissions, making dying, which was once an "otherworld journey" and "community affair", an increasingly private, hidden, professionalised and institutionalised event.[3] Access to high-quality, culturally responsive palliative care is variable.[4] Most New Zealanders (65%, increasing to over 90% for those aged over 85 years) are likely to die in an institutionalised setting—either in hospital or, increasingly, in aged residential care.[5] In the *Palliative Care Action Plan*, Aotearoa New Zealand prioritised responding to the voices of people with palliative care needs and committed to implementing culturally appropriate responses to meet the needs of different cultural and ethnic groups.[4] Previous palliative care research with Māori has highlighted that a Western biomedical approach does not meet the cultural palliative care needs of Indigenous peoples. We acknowledge the legitimacy and imperative to address this, mindful of the intergenerational impacts of colonisation, and the status of Māori as the tangata whenua of Aotearoa New Zealand. We also anticipate that diverse groups of migrant people have experiences that are similar, as well as different, to those of their primary Te Tiriti partner, and these require attention to achieve population health equity.

Over-exposed yet unseen

Aotearoa New Zealand's census population statistics indicate increasing populations of ethnic minority communities (EMCs), comprised of highly diverse ethnic groups identifying with Asian, Middle Eastern, Latin American and African (MELAA) origins.[6] EMCs have grown from 10% of Aotearoa New Zealand's total population in 2006 to 16% in 2018, and over 200 ethnicities are reported in Auckland alone. However, data, research and national policies that specifically address their core healthcare needs, including at end-of-life, is scant.[4] Reported deaths in EMCs in Aotearoa New Zealand recorded as "Asian" at

level 1 ethnicity reporting account for 4.7% of total deaths and are projected to rise to 10.4% by 2043.[5] The default to homogenise and report meaningless categories such as "Asian", "MELAA" or "other" in many publicly available reports and research publications in Aotearoa New Zealand masks the highly diverse experiences of Aotearoa New Zealand's EMCs. These limitations are consistent with arguments in World Health Organization (WHO) and Lancet Global Health reports[7,8] that highlight the virtual absence globally of robust data to support the needs of migrant populations that are "*overexposed* [to risks] *yet unseen*" despite clear health inequities compared to host populations.[8]

Overseas, inequities in care of the dying are reported in non-white ethnic groups who are more likely to die in intensive care, receive invasive procedures in the last 6 months of life and have poorer access and uptake of hospice services and participation in advance care planning compared to host populations.[9–12] A narrative literature review found that preferences of EMCs at end-of-life were influenced by migration experiences (e.g., exposure to racism, discrimination, acculturation level, migration trauma, enforced poverty, fragmented cultural identity), age, gender, cultural and spiritual practices, generational differences and level of available social support and healthcare.[13] Tensions between individualism and familism, religious and secular positions, perceived power imbalances between minority and dominant cultures and fear and mistrust in healthcare institutions were also reported. Self-management through prayer, spiritual healers, herbal remedies and traditional medicine was viewed as important. In addition, a recent integrative review of barriers to equitable access to healthcare in Aotearoa New Zealand for migrants and refugees reported attitudinal barriers (lack of culturally competent healthcare providers, discrimination and personal sociocultural factors) and structural barriers (cost of healthcare, accessibility to interpreters, length of appointments and difficulties navigating the health system).[14] Although studies suggested death was perceived as taboo in some EMCs with a predominant collectivist approach to decision making and cultural value of filial piety, experiences were varied and heterogeneous; there is no "one size fits all" approach to end-of-life care, which unfolds in relation to others and beyond the individual. Other factors reported to promote positive experiences at end-of-life included access to professional interpreters, language aids, cultural navigators or mediators of similar culture or ethnicity, healthcare professionals spending time with whānau, involvement of EMCs in policy making and being accompanied by someone close to advocate and communicate their needs.[13]

Recommendations for an inclusive, equitable health service for migrants and refugees included promoting a sense of belonging, enabling a whole-of-society approach through stakeholder collaboration and national policies that specifically address healthcare needs of EMCs.[14] Many systematic reviews also recommended the need for culturally appropriate, relational, whānau-centred care focussed on compassion, humility and respectful listening in discussions at end-of-life.[13] As Aotearoa New Zealand continues to grow and evolve as a multi-ethnocultural society, it becomes increasingly imperative to: a) better understand and respond to the diverse needs and aspirations of people from EMCs living with life-limiting illness so they can die well with dignity, b) re-vision the way EMCs, who informally carry the bulk of caring yet are often unprepared, are supported to care for whānau at end-of-life, and c) equip our current and future health and community workforce to meet and support the needs and aspirations of EMCs to die well with cultural safety.

The "good death" no longer good enough?

An integrative literature review supports the argument that the concept of the "good death" may no longer be "good enough" in an increasingly Westernised neoliberal society in which individual autonomy and control are central values.[15] The good death is challenged as a form of social control and means for controlling the dying process, designed to ease care demands for health professionals, and incongruent to the desires of dying individuals. The concept is also threatened by an increasingly ageing population with unpredictable illness trajectories due to chronic illnesses that make it difficult to know when dying begins (the "ambiguous dying syndrome"), culminating in a theme of denial of dying and a dominant discourse on assisted suicide to control timing of death. The *End of Life Choice Act* was legislated in Aotearoa New Zealand on 7 November 2021, making assisted dying a funded option for all New Zealanders with a terminal illness.[16]

It is unsurprising that EMCs have poorer

uptake of hospice services and participation in advance care planning,[9] as both practices emerged from Western philosophical concepts of autonomy, choice, self-determination and neoliberal frameworks for managing dying, and do not reflect more interpersonal, relational and family-oriented approaches as found in cross-cultural contexts. Conversations focussing on "what matters most" have been proposed by Abel et al.[17] as an alternative, inclusive, public health approach to advance care planning that recognises the experience of "living with dying" and the linkages between identity (sense of value through compassion, love, laughter and friendship), place and supportive social environments, and well-being, as opposed to crisis planning and final treatment options.[17] It describes a "process of positive choices" that offer hope, shared understanding and "*affirmation of what each person wants in the life that remains and how best the network around them is able to support this*."

Bendle states: "*Death may be purchased and consumed, valued and depreciated, managed and administered in a fashion entirely consistent with any other commodity or bureaucratic transaction under 'free market' principles, with ever-increasing superficiality and lack of lasting meaning or significance*."[18] The review concludes with the need "*to reframe and reclaim dying*" towards the positive aspects of dying, recognising it as an important part of living and that by denying dying, opportunities for individual growth, validation and celebration of lived experiences, and to find meaning and memories to carry into subsequent generations, may be lost.[15]

Benefits of death awareness

Recent existential crises and multiple losses (financial, social and personal security) due to the COVID-19 pandemic and severe climatic events have been described as a "*collective calamity for meaning*." They threaten a sense of self-efficacy and control and increase awareness of the inherent impermanence and uncertain nature of life and death. In contrast, the potential life-enriching impact of increased death awareness, as evident following the COVID-19 pandemic, can motivate people to make significant changes towards greater authenticity, appreciation of self/others, and meaning and purpose.[19] It is associated with improved psychological and physical health (reduced stress, increased immune functioning, longevity and interpersonal relationships) and a richer existential, spiritual life that contributes to wisdom.[20] Specific cultural/spiritual beliefs that subscribe to more holistic theories of the world or where death awareness is actively encouraged may also act as buffers against death anxiety.[21] Meaning-making strategies including recounting and reframing one's story, meaningful encounters with others to explore evolving self and expressive writing may also provide means of rediscovering meaning in life at times of uncertainty.[22] As Pacheco states: "*Some of us might only become deeply aware of our life when faced with a near-death experience or severe illness. But we don't need to wait for a terminal diagnosis. We can begin right here, right now, wherever we are, and start to see mindfulness of death as a precursor to truly living. The benefits of this type of contemplation are numerous and worth exploring*."[21]

A call to reclaim dying

Globally, there is increasing call to reclaim dying as an important part of living: "*To be present in daily life, spoken about and accepted, not hidden away*."[23] Compassionate Communities, a public health promotion approach to palliative and end-of-life care, fosters this by de-professionalising death, dying and grieving, raising public awareness and death literacy, building sustainable network-based caring capacity within communities by supporting solidarity among community members at end-of-life and giving voice to and celebrating a community's spiritual traditions and storytellers.[24]

There is a growing international movement of death positivity through public health initiatives, book and media publications, death cafes, death doulas and a growing number of Facebook groups, dedicated to increasing society's awareness of dying and to give authority and voice to the experiential knowledge of community members as equal to, if not more valid than, professional knowledge.[9,23]

The power of story (pūrākau)

The importance of celebrating the cultural and spiritual lived experiences relating to death, post-death care of the deceased and their family, reconciling a sense of belonging and reclaiming and passing on knowledge of traditional care customs to strengthen whānau at end-of-life has been explored in EMCs and in Indigenous communities.[25] As death was considered normal and an inevitable process that was not the end but a transition to the next life, "preparing the spirit"

was most important. This involved a process of understanding "where we come from", including one's beliefs, values and perspectives about "the heart and spirit" or essence of life. Sickness was viewed as more than a disease and reflected historical collective and individual pain, both of which harmed the spirit. Healing was through connecting with other people's pain, which enabled individuals to cope with the suffering in their experience, in turn allowing them to come to a sense of acceptance, peace and connection with "*greater beings, kin, previously deceased family members, and the homeland*" and strengthen the spirit to enable its journey forward.[25]

As human beings, we are by nature meaning-making creatures who are defined by the stories we create. Storytelling is an age-old tradition that brings people together through shared knowledge and experience. For Māori, stories (pūrākau) are viewed as a powerful means of reclaiming and promoting Indigenous and collective knowledge where the pū (roots) and rākau (tree) can "*help people flourish when they are nurtured and shared*." They are individual and fluid, as experiential understandings change over time and fulfil our human need for connection. They can motivate change in behaviours, attitudes and beliefs; bring together different people, places and realities; uncover complexities and challenge established knowledge and practices of knowing and doing.[26]

Urgent need for data and research

There is an urgent need for comprehensive ethnicity data and high-quality research on EMCs, and translation into policy and action, as recommended by WHO's 2023 first global research agenda on health, migration and displacement.[7] Research questions include but are not limited to understanding: a) what dying well means and what matters most for people from EMCs living with life-limiting illness in Aotearoa New Zealand, and their whānau, including their end-of-life care experiences, preferences and needs, b) how migration experiences (e.g., migration trauma, and loss, acculturation, racism, discrimination, enforced poverty, fragmented cultural identity), cultural/spiritual practices, generational status and other existential concerns impact on these experiences, and c) the barriers, challenges and solutions to providing culturally safe end-of-life care to EMCs. One possible research methodology to explore these questions is digital storytelling, which has been successfully used for exploring palliative care, and traditional and contemporary preferences for optimal end-of-life care in Indigenous Māori whānau.[26] Due to its participatory and co-productive nature, it has the potential to break down power hierarchies, befitting and benefitting the communities and cultures in which research takes place while enabling a public health approach. It is often used when working with vulnerable, marginalised, under-served groups and in exploring sensitive topics. Its strength lies in its simplicity, accessibility and intention "*to stimulate reflection, deeper learning and perhaps transformation*."[27]

Cultural safety and community engagement

Many reviews exploring the end-of-life experiences of EMCs speak of the need for culturally appropriate, holistic relational care that focusses on compassion, humility and listening in order to build mutual trust, respect and understanding. While health professionals were once asked to demonstrate cultural competency as part of their training, it is now recognised that this is limited due to the constant evolving nature of culture and the focus on knowledge that may lead to assumptions and stereotypical views.[28,29] In contrast, cultural safety and cultural humility involve an ongoing process of self-exploration and self-reflection, combined with a willingness to learn about others for who they are, to honour their views, beliefs, customs and values, towards building honest and trustworthy relationships. Cultural safety recognises that culture is ever-changing and uniquely defined in the context of a person's life experience and beliefs. It encourages health professionals and health systems and organisations to proactively engage with caring curiosity about each person and how they fit into a broader cultural community. It also involves a commitment to lifelong learning and reflection on addressing the power imbalances that exist in healthcare by focussing on respectful egoless dialogue, examining white privilege and power, and sharing this with those who have less, in particular Māori as tangata whenua and, by extension, migrants to Aotearoa New Zealand.[28]

Cultural safety also involves directly engaging with individuals and communities in their healthcare and decision making, giving them power to comment on practices and policies, and to contribute to the achievement of positive health outcomes and experiences. The need for community

engagement and collaboration on practice and policies is supported by a recent integrative review of barriers to equitable access to healthcare for migrants and refugees,[14] and the Compassionate Communities approach to palliative and end-of-life care.[24] A recent qualitative study exploring enablers and barriers to culturally safe end-of-life care highlighted the need for appropriate resourcing, and value and recognition of Māori health practitioners undertaking unpaid and often unrecognised cultural and connecting work supporting culturally safe end-of-life care for Māori patients and their whānau that was often time consuming and not remunerated.[30] The study noted how structural-level change related to institutional power shifts and racism, and a supportive leadership, were important to realise the aspirations of delivering culturally safe, equitable palliative and end-of-life care. The engagement of EMCs in service development and participatory research can support more authentic understandings of the needs and preferences of people from diverse cultures and enhance the development of valued and trusting relationships between healthcare providers and the diverse communities they serve.

Conclusion

Dying well is a universal aspiration, yet its interpretation and realisation largely remains unknown. Most New Zealanders, currently, are likely to die in hospital or in aged residential care. The notion of the "good death" is strongly argued in the context of today's increasingly diverse, multicultural society where views, beliefs and attitudes to death and dying are widely heterogeneous, even within similar ethnic and cultural groups. There is no "one size fits all" approach to death, yet there appears to be a common thread among the experiences of the dying—the need to be seen, deeply understood, connected to, cared for and loved in a profoundly intimate, individual and relational way.

Exploring the myriad of cultural and spiritual diversity, and unique perspectives on death and dying, in Aotearoa New Zealand's diverse EMCs may help to enrich our understanding of the tapestry of end-of-life experiences. In addition, de-professionalising death and exploring dying, grief and loss in our communities and everyday lives may help us to understand what it means to live and die well in an increasingly complex, volatile and uncertain world, and reach the possibility and potential life-enriching benefits of death's presence in everyday life. Aotearoa New Zealand has real opportunity and potential to reclaim and reframe dying, to give voice to and celebrate our community spiritual traditions and storytellers, towards the provision of culturally safe end-of-life care for all New Zealanders that truly honours the diverse range of human experiences.

COMPETING INTERESTS
Nil.

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A rare case of severe constrictive pericarditis post-COVID requiring pericardiectomy

Mark O Pottier, Emily R Hill, John G Lainchbury, Ian G Crozier

Cardiovascular sequelae of COVID-19 are well documented but poorly understood. A rare but devastating sequela is that of constrictive pericarditis. To our knowledge, this is the first case described in Australasia.

History

A previously healthy 70-year-old male presented 3 weeks post-COVID with acute pericarditis with pericardial effusion and treated as acute pericarditis. Ten months later he developed severe oedema with anasarca. He was managed in another centre as undifferentiated heart failure, but following failure to respond to diuretic therapy was transferred to our centre. On arrival he had a markedly elevated jugular venous pressure, and severe oedema. The brain natriuretic peptide (BNP) was only marginally abnormal at 69pmol/L (normal <29, indeterminate 30–80pmol/L). The echocardiogram suggested pericardial constriction with septal bounce, E wave greater than A wave on transmitral Doppler flow (E/A ratio 1.8), medial mitral annulus tissue Doppler E' greater than lateral E' (annulus reversus) and dilation of the inferior vena cava without respiratory collapse. The computerised tomographic scan showed marked pericardial thickening (Figure 1). We diagnosed him as having severe constrictive pericarditis.

Our patient proceeded for pericardiectomy after not responding to medical therapy. Initial central venous pressure was greater than 20cmH2O. He was found to have a markedly thickened anterior pericardium of 8mm adhered to the right ventricle from outflow tract to the atrioventricular groove (Figure 2). He underwent an anterior visceral pericardial fibrosis peel. Following this there was an immediate improvement in heart expansion and the central venous pressure dropped to under 10cmH2O. Histology showed dense fibrous thickening with a small amount of admixed fibrin, consistent with organising haemorrhagic effusion.

Post-operatively our patient had markedly improved haemodynamics and was discharged 7 days post-operatively. He was maintained on furosemide 40mg and spironolactone 25mg daily.

Discussion

We believe that our patient developed constrictive pericarditis due to COVID-19, given early evidence of pericarditis after acute infection and no other cause being identified.

To our knowledge, only five other cases of constrictive pericarditis secondary to acute COVID-19 infection have been reported.[1–5] Only one other case reported describes similar irreversible constrictive pericarditis requiring pericardiectomy.

This case was initially diagnosed as congestive heart failure. Due to the rarity of constrictive pericarditis post-COVID, the features of constrictive pericarditis were overlooked. However, the markedly elevated venous pressure coupled with an indeterminate BNP, combined with features of pericardial constriction on echocardiogram (septal bounce, a high E/A ratio and annulus reversus) in a patient with heart failure should raise suspicion of constrictive pericarditis. Respiratory variation (greater than 25% with inspiration) of transmitral Doppler E velocity is another feature of constrictive pericarditis but was not specifically looked for on the initial echocardiogram, emphasising the importance of sonographers and echocardiologists recognising the possibility of constrictive pericarditis. Annulus reversus likely represents the tethering of the lateral mitral annulus to thickened adjacent pericardium, causing increased motion of the medial annulus relative to the lateral annulus.[6] Interestingly, a repeat echo performed a few days post-operatively showed resolution of the annulus reversus. This appears to only occur in 50% of patients.[7] This can be explained by the removal of constraints of lateral annular expansion, thus reducing the increased

longitudinal movement of the medial annulus.

Conclusion

We describe a rare case of constrictive pericarditis post-acute COVID-19 infection with eventual pericardiectomy. This is an important case to highlight the complexities of the cardiovascular sequelae of COVID-19. It also highlights the importance of considering pericardial constriction as a mode of heart failure in patients recovered from COVID-19.

Figure 1: CT scan showing thickened anterior pericardium approximately 5.5mm in thickness.

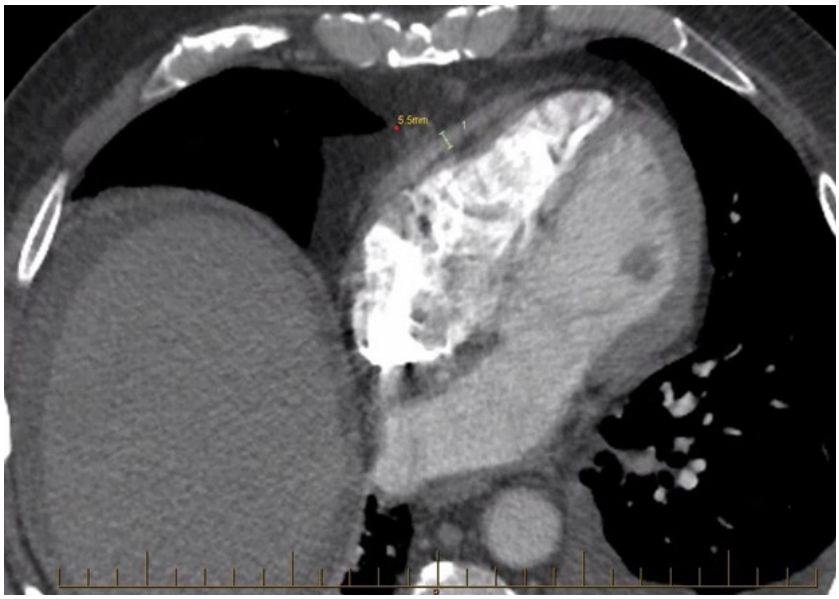
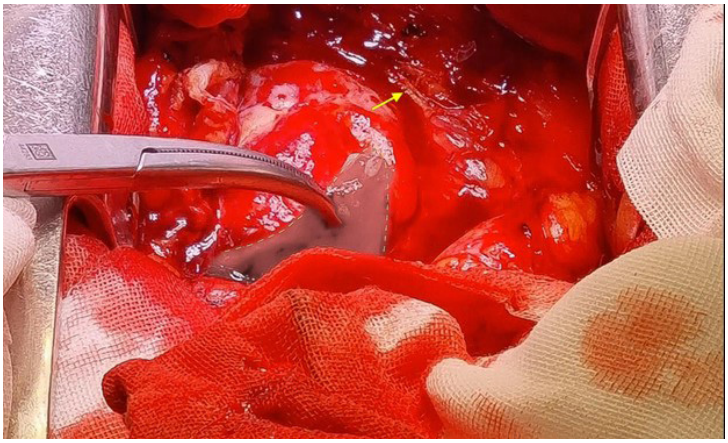


Figure 2: Intra-operative images. Enhanced to increase visualisation of stiffened anterior pericardium (dotted line). Arrow showing resected pericardium.



COMPETING INTERESTS
Nil.

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The Danger of Interruption of Insulin Treatment.

NZMJ, 1924

By H. Bayldon Ewen, M.B.

Very little has as yet appeared in the journals concerning the grave danger which confronts the diabetic when, from any cause, insulin is withheld. *Blum*, *Carlier*, and *Swab* (*Bulletins de la Soc. Med. des Hopitaux*) record the case of a man who suffered from diabetes for five years and had been able to resume work as the result of insulin treatment. His supply of insulin ran out, and three days later vomiting became so severe that the stomach was intolerant even of liquid. By the sixth day he was comatose, and died in spite of the injection of 160 units of insulin.

As a somewhat similar case has occurred in connection with the Diabetic Department of the Wellington Hospital it would seem advisable to draw the attention of the profession in New Zealand to this very real danger. The patient, whose age was 52, was admitted on 24th November, 1923, 21 months after the onset of symptoms. She had lost 51lb. in weight. There was no intercurrent affection. The average excretion of sugar per day on a basal metabolic diet of 1000 calories was 24 grammes. She was discharged on 29th December, 1923, on a ketogenic-antiketogenic diet of 1900 calories with 40 units of insulin per day. On this balance there was only a trace of glycosuria, no acetone, and a blood sugar percentage of .196. As she came from the country the details of subsequent events are not fully known, but for some reason she left off taking the insulin soon after leaving hospital, and died in coma about a fortnight later.

An analogous case may be mentioned. Through a certain batch of insulin being inactive one of our patients was re-admitted in a state of coma. Fortunately a supply of insulin of a more reliable manufacture arrived that morning, and by the prompt administration of 70 units he recovered.

It would seem that a fulminating acidosis is produced when insulin is suddenly cut off, and Nature has not time to replace the metabolism of carbohydrates by that of fats and proteins. We always advise our patients to reduce their diet by one-third and to rest should their supply of insulin run out. But even this precaution may not be sufficient.

Another serious danger is the inset of some other disease, accompanied by vomiting and diarrhœa. If the patient is unable to take the prescribed diet, should insulin be withheld? Our advice, based on that given in Toronto, has been to stop the insulin until food can again be taken. So far we have not had to deal with this complication, but one of our pntients, who had been taking the inactive insulin referred to above, came back in coma and died from what proved to be uræmia. It was only after the exhibition of an enormous dose of insulin (360 units) that she was rendered sugar-free. But in spite of this she died about 24 hours later.

The authors referred to above quote an instance of a diabetic under insulin treatment who developed phlebitis first of the left, and then of the right, femoral vein. As a result he felt very weak and reduced the dose of insulin, but in 48 hours acidosis was marked. Three hundred and eighty units of insulin were required to overcome this in 24 hours.

It would seem that the dose of insulin which is sufficient in health is too small when some other disease intervenes. Probably the exhibition of alkalis in large doses in addition to insulin is indicated.

We would suggest to the Department of Health the advisability of stocking insulin for distribution to hospitals. We know that no laboratory can absolutely guarantee the potency of this valuable remedy, and, where it is found that a batch of one manufacture is inactive (as instanced above), it would be invaluable to be able to procure insulin of a different manufacture from a central depot. The product of the Connaught Serum Laboratories, Toronto, Canada, has, in our hands, proved most reliable; and it was through receiving a supply from this source that we were able to save the life

of the patient referred to above, and to cut short the rapidly increasing hyperglæmia in a number of others. It is to be hoped that the Department will very soon see its way to keep stocks of insulin manufactured in at least two different laboratories.

A point not altogether relevant to our subject, but nevertheless of interest, concerns the oft-repeated statement that a diabetic, even when on insulin, cannot do manual labour.

A young man of 25 came under our care on 11th December, 1923, with a history of two years' dieting under the *Allen* regime. His weight was 120lb., and his blood sugar on a diet of 2400 calories was .202. To-day his weight is 150lb. (height 5ft. 8½in.), and his blood sugar .164. He is a farm labourer, doing heavy work in the back-blocks beyond Taumarunui. His diet has a caloric value of 3000 and he is taking 20 units of insulin per day. He looks and feels in perfect health. Perhaps this is but a case of the exception proving the rule.