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100 years ago in the *NZMJ*

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Parents and caregivers experience in managing children's medicines after discharge from a New Zealand hospital

Rajeshni Naidu, Debbie Bassett-Clarke, Ross Nicholson, June Tordoff

Managing children's medicines by parents/caregivers at home can be challenging. This study, carried out at one of the children's hospitals in New Zealand, shows how parents/caregivers from different ethnic backgrounds, including Māori and Pacific Island, require appropriate and consistent information on discharge medicines from doctors, nurses and pharmacists for safe delivery of medicines to their children at home. The study demonstrates how parents/caregivers did not have appropriate measuring equipment to give medicines safely to their children at home. A standardised discharge process is needed to ensure parents/caregivers are given clear, consistent and easy-to-understand information on their children's medicines. It is important for health professionals to use health literacy strategies including written information, using interpreters and providing measuring equipment with instructions to improve parent/caregiver understanding and management of their children's medicines at home.

Defining rural in Aotearoa New Zealand: a novel geographic classification for health purposes

Jesse Whitehead, Gabrielle Davie, Brandon de Graaf, Sue Crengle, David Fearnley, Michelle Smith, Ross Lawrenson, Garry Nixon

A joint project by the universities of Otago and Waikato to reclassify what is considered rural in a health context will provide more accurate data of differences in health outcomes between rural and urban areas. The study, *Defining rural in Aotearoa New Zealand: A novel geographic classification for health purposes*, published in today's *New Zealand Medical Journal*, says rurality in the New Zealand health context has been inappropriately classified to date—in the past two decades it has been classified in more than 30 different ways in health literature—producing a confusing and potentially inaccurate body of evidence on rural health. The newly developed five-level Geographical Classification for Health (GCH) addresses longstanding concerns about the way rural health outcomes have been measured in New Zealand. The GCH is technically robust and uses the same building blocks and methodology as the Statistics New Zealand classifications, but the population and travel time framework used to create the different categories takes health into consideration, and importantly it was modified in response to feedback from those working in rural health. There is some early evidence that the GCH rural population has different health outcomes. When applied to the national mortality collection, the GCH shows that unadjusted mortality rates in rural areas are 21% higher than in urban areas—a difference that is not shown with generic classifications. The GCH will provide a clearer picture of the health of rural New Zealanders and could ultimately improve rural healthcare.

Motivators and barriers to general surgery as a career among junior doctors and medical students in New Zealand

Leah Boyle, Adam Payne, Sharon Jay, Jeremy Rossaak

Interest in choosing a general surgery as a career is affected by a range of motivators and perceived barriers. These differ between gender and ethnicities but the most important factors are clinical and practical aspects and work–life balance. Significant barriers are the perceived training hours and being overwhelmed. There is a perceived gender and ethnicity bias in general surgery. All the above factors need to be taken into account in order to try and increase the interest in general surgery as a career.

A comparison of the performance of saliva and nasopharyngeal nucleic acid amplification testing for the detection of SARS-CoV-2 in New Zealand

Gary McAuliffe, Timothy Blackmore, Juliet Elvy, Shivani Fox-Lewis, Brent Gilpin, Jenny Grant, Radhika Nagappan, Erasmus Smit, Chor Ee Tan, Fernalynn Tiongko, James Ussher

We compared detection of SARS-CoV-2 from paired nasopharyngeal swabs (NPS) and saliva in Auckland, Wellington and Dunedin. One hundred and ninety-six paired samples were tested, of which 43/46 (93%) tested positive from NPS, and 42/46 (91%) from saliva, indicating excellent overall concordance.

“I teach them. I have no choice”: experiences of primary care among transgender people in Aotearoa New Zealand

Kyle K H Tan, Rona Carroll, Gareth J Treharne, Jack L Byrne, Jaimie F Veale

This study found that transgender people have a harder time than other people when it comes to getting healthcare from a primary care provider. They are more likely to feel like their doctor does not understand them, to have more confidence in their GPs, and to report that GPs involve them in decisions about their care. They are also more likely to have problems with transportation and cost. The study also found that transgender people's experiences are shaped by their healthcare environment and the resources they have available to them.

Smokefree and vapefree streets: high levels of support from tourists, residents and businesses, implications for tourist-destination communities in New Zealand

David Brinson, Charlotte Ward, Cheryl Ford, Annabel Begg

This study was designed to evaluate the attitudes of local businesses, residents, and visitors regarding the trial of a voluntary smokefree and vapefree zone covering the central business streets of a popular tourist town in the South Island of New Zealand, Hanmer Springs. Considerable effort was directed towards accurately measuring the level of support for the initiative in Hanmer Springs, by seeking opinions from nearly 1,000 respondents across a broad range of stakeholder groups, using a variety of survey methods. Results indicated strong public support for current smokefree outdoor areas to also be vapefree. The initiative was particularly attractive to visitors, with 95% of visitors surveyed indicating that they would be more likely or as likely to visit other places in New Zealand with similar smokefree and vapefree outdoor areas. We conclude that smokefree and vapefree zones will have an overall positive impact over the long term, which will support New Zealand’s smokefree 2025 goal.

Utility of data linkage for orthopaedic service planning in the paediatric population with cerebral palsy at Starship Children’s Hospital

Wendy He, Alexandra Sorhage, Nichola C Wilson, N Susan Stott

In this study, the surgical procedures performed at Starship Children’s Hospital over a five-year period were described and demographic data were obtained via data linkage. It showed that data linkage could be used at the national level to identify regional differences and assist with surgical planning. Furthermore, potential inequities in the health system were identified. Further research with Māori Health researchers and the NZCPR is needed to investigate this matter further.

Children’s perspectives on the wicked problem of child poverty in Aotearoa New Zealand: a wearable camera study

Ryan Gage, Tim Chambers, Moira Smith, Christina McKerchar, Viliami Puloka, Amber Pearson, Ichiro Kawachi, Louise Signal

What does poverty look like from a child’s perspective? In this 2014/15 study 168 12-year-olds wore a camera for four days that automatically recorded the world around them every seven seconds. We compared the images of the children in high and low deprivation to better understand what it means for children to live in poverty. Children in poverty appear to have fewer types of fruit and vegetables, educational materials and physical activity equipment. They live in homes with more structural problems and mould, less fixed heating and computers. Since data was collected, there have been improvements to housing and a cost-of-living payment to low-income earners was announced this week. Yet, the complex problem of child poverty remains in Aotearoa damaging the health and wellbeing of our children.

NZMJ: under new ownership

Frank Frizelle, Kiki Maoate

The *New Zealand Medical Journal* (*NZMJ*) is now owned by the Pasifika Medical Association Group (PMAG). The situation of New Zealand Medical Association's (NZMA) demise was outlined in our recent editorial.[1] Now, from the ashes of the NZMA, the PMAG has acquired the *NZMJ*, and like the phoenix of classical mythology we live on, now with renewed energy and resources.

The PMAG is an organisation that people may be unfamiliar with. It was formed in 1996 by a group of Pasifika health professionals who identified a need for an association with the purpose of "providing opportunities to enable Pasifika peoples to reach their aspirations".[2] In his press release, Chairperson of the PMAG Board Dr Kiki Maoate acknowledges the uniqueness and value of the *NZMJ* to Aotearoa New Zealand's society, saying: "the acquisition was intentional and serves a wider purpose".[3] The *NZMJ* will be governed and managed by the PMAG.

The *NZMJ* was first published 47 years after the signing of the Te Tiriti o Waitangi. When the *Journal* was first published, it aimed explore the health issues relevant to New Zealand. In many ways, the goals are aligned with what we aim to do today; it is just in how we do it that has changed. In recent years, there has been increasing emphasis on Hauora Māori outcomes and equity, which is important to maintain.[4,5] The PMAG, as the new owners, will also want emphasis on Pasifika health outcomes and equity. This improved and stronger connection with Pasifika peoples brings forth a real opportunity for the *Journal* to explore and strengthen our relationship. We encourage Pasifika researchers and health professionals to be involved with the *NZMJ*—to have more work published in it, with the aims of improving health and wellbeing dialogues for, and of, Pasifika peoples.

The *NZMJ* readership and supporters can rest assured that the goals and philosophies, the Editor in Chief, the Editorial Board, the handling of manuscripts, peer review and editorial freedom remain largely unchanged, if not improved. Amongst these improvements are the current upgrading of the webpage, along with the additions of the PMAG branding. Infrastructural changes will improve access and communications which, in turn, will endeavour to make the *Journal* more accessible and appealing to a broader audience. There are also a number of transitional matters still in the process of being resolved, such as firewall access, subscriptions, and media and general communications, etc. At the time of writing, access is as per NZMA members' previous *NZMJ* login details and passwords; as we enter this new phase, this is being debated and discussed. We are exploring how we might improve access to the *Journal* for as many people as possible; however, we are aware of the need to maintain the financial integrity of the *Journal*.

The *NZMJ* is alive and well-supported within the PMAG family, and we look forward to your ongoing contributions and support.

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COMPETING INTERESTS
Nil.

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Parents and caregivers experience in managing children's medicines after discharge from a New Zealand hospital

Rajeshni Naidu, Debbie Bassett-Clarke, Ross Nicholson, June Tordoff

ABSTRACT

AIM: To investigate the level of understanding parents/caregivers have regarding prescribed medicines for their sick children, and how they manage these medicines at home following hospital discharge.

METHODS: English-speaking parents/caregivers of sick children were recruited if their child was admitted to Middlemore Hospital in New Zealand and prescribed two liquid medicines, specifically an analgesic and an antibiotic. A questionnaire was developed and used to interview parents/caregivers on three separate occasions. The questionnaire was firstly administered during their hospital stay; secondly, by telephone post-discharge; and thirdly via a home visit two to three days after the estimated completion date of the antibiotic course.

RESULTS: Eighteen participants from the five main ethnic groups (Pacific Island n=7, NZ European n=5, Māori n=4, Asian n=2) completed all three interviews. Parents/caregivers had a reasonable understanding of the purpose of the medicines prescribed. Doctors, nurses and pharmacists provided variable medicines information to parents/caregivers on hospital discharge. Parents/caregivers used a variety of measuring equipment at home, but over a quarter (28%) were not supplied with an oral syringe to measure appropriate doses of medicines at home, and some lacked knowledge on safe storage and appropriate disposal of medicines.

CONCLUSION: This study found variation and gaps in the information for medicines provided at discharge. To facilitate the safe use of medicines, consistent and clear information about the use, storage and disposal of medicines needs to be provided by all healthcare professionals involved; and accurate measuring equipment should be provided free of charge with instructions.

Children require special consideration for prescribing or administering medicines, especially on discharge from hospital, when parents/caregivers are expected to manage medicines at home. Lack of safe and effective data on medicines use in children,[1] makes it more complex.[2] Factors such as drug formulation, palatability, appearance, ease of administration and parents/caregivers' perceptions of medicines, all affect adherence.[2] Especially, as some liquids are formulated from crushed tablets,[3] have a short expiry, and require refrigeration.[2]

Parents/caregivers may require further education on how to safely administer medicines to children, because medication errors in children have been reported to be three times more likely than in adults,[4] and more commonly associated with measuring incorrect dose volumes.[5] Errors are often due to inappropriate measuring equipment,[6] and standardised measuring devices (oral syringes, measuring cups or calibrated measuring spoons) are preferred over non-standard equipment, such as kitchen spoons.[7]

Parents/caregivers with lower health literacy levels have also previously been identified as most likely to make dosing errors.[8]

Our study aimed to identify how well parents/caregivers in the Counties Manukau Health (CMH) region understood their children's discharge medicines and how they manage medicines at home.

Methods

The study was approved by the University of Otago Human Ethics Committee (H16/051), and CMH.

This study was designed and conducted by RNa as part of a master's degree in clinical pharmacy. Supervision and advice were provided by DB-C (clinical pharmacist), RNi (consultant paediatrician), and JT (academic pharmacist).

Recruitment for this prospective, observational study was conducted on paediatric wards at Middlemore Hospital, CMH from 27 June to 2 December 2016. The study population were parents/caregivers of children ≤14 years old, diagnosed with skin or respiratory infections and prescribed two liquid medicines (an antibiotic and analgesic) on a discharge prescription. People who did not speak English, and children with complex medical histories or on other medicines (long- or short-term) were excluded from the study.

The aim was to recruit 20 participants with a

similar ethnic distribution to CMH region (i.e., 41% Pacific Island (n=8), 24% Māori (n=5), 24% New Zealand (NZ) European (n=5) and 11% Asian (n=2)). Potential participants were approached by nurses, handed a participant information sheet and those interested were then approached by the researcher. They were asked to sign a consent form, give permission to record their interviews and to allow photographs to be taken of measuring equipment and medicine storage places in their homes. Participants were invited to have a support person (friend/whānau) present during the interviews.

A three-part questionnaire was purposively developed and used by the researcher to complete the interviews with the participants. Before use with the participants, the questionnaire was pilot tested by five parents/caregivers who had previously administered liquid medicines to their children and amended in the light of their comments. The researcher administered the questionnaire by reading the questions to each participant and writing down their answers.

Part A of the questionnaire was completed while the participant's child was still on the ward; Part B was completed by a telephone interview two to three days post-discharge; and Part C was completed approximately two to three days after estimated completion of antibiotic course.

Data was analysed quantitatively using descriptive statistics; and qualitatively using conventional content (thematic) analysis of responses/comments.[9] The questionnaire data was analysed manually, and examples of responses/comments are presented in italics in this article.

Results

During the study, 55 potential participants were identified and 39 agreed to participate. Due to recruitment and time constraints, the study ceased when 18 participants from the five main ethnicities completed all three interviews.

The demographics are described (see Table 1) with further ethnic distribution of the participants as Pacific Island – Samoan (3), Tongan (1), Niuean (2), Samoan/Cook Island/Tongan (1); Māori – NZ Māori (1), NZ Māori/Niuean (1), NZ Māori /NZ European (1), NZ Māori /Samoan (1); NZ European – NZ European (4), NZ European/Chinese/ NZ Māori (1) and Asian – Indian (1), Chinese (1).

The participants' children were three months to seven years old. Ten were diagnosed with a respiratory infection (pneumonia) and prescribed antibiotic suspensions either amoxicillin (8), amoxicillin/clavulanic acid (1) or erythromycin (1). Eight had a skin infection (cellulitis or abscess) and were prescribed amoxicillin/clavulanic acid (5) or cephalexin (3). All children were also prescribed paracetamol suspension.

Doctors handed out prescriptions to most participants (14, 78%) on discharge and nurses gave to the remaining participants. The types of medicines information provided by health care professionals (HCPs) from hospital on discharge and from community pharmacy varied (see Table 2).

Three participants stated that they were not provided with any information on medicines on hospital discharge while another two could not recall. Two participants stated that no information was provided by community pharmacy, two could not recall and on two occasions partners of participants collected medicines from pharmacy so participants were not aware of information provided.

Sixteen participants (89%) reported that they made no attempt to obtain further information about the discharge medicines from any other sources when they reached home.

Compliance with discharge medicines

At the time of the home visit 15 (83%) participants reported that the prescribed course of antibiotic was complete. Reasons given for non-completion were: *"The baby would go to sleep and miss his evening dose", "I forgot to take the child's medicine to preschool missing a lunchtime dose"*; and *"I simply forgot".*

Knowledge about analgesics and antibiotics

Seventeen (94%) participants knew the purpose of paracetamol and 15 (83%) knew how often or when to give.

Descriptions for the purpose of paracetamol included: pain and fever (15); pain (1); fever, flu, runny nose (1); and sick or headaches in adults, not sure in children (1); and described the times that they administered paracetamol *"only for [when] unsettled", "not if alright", "only when needed", "only when she is in pain", "whenever temp is high", "for example for fever"* and *"only when it's a problem".*

All 18 (100%) participants knew the purpose of antibiotics (for pneumonia or skin infection) and thirteen (72%) were able to recall the duration. Two themes were identified.

- Infection: described as "for infection", "antibiotic", "for pneumonia", "to fight infection in leg", "chest infection" and "to kill bacteria".
- Healing: described as "to heal the scars" and "for healing".

Table 1: Demographics of participants (n=18).

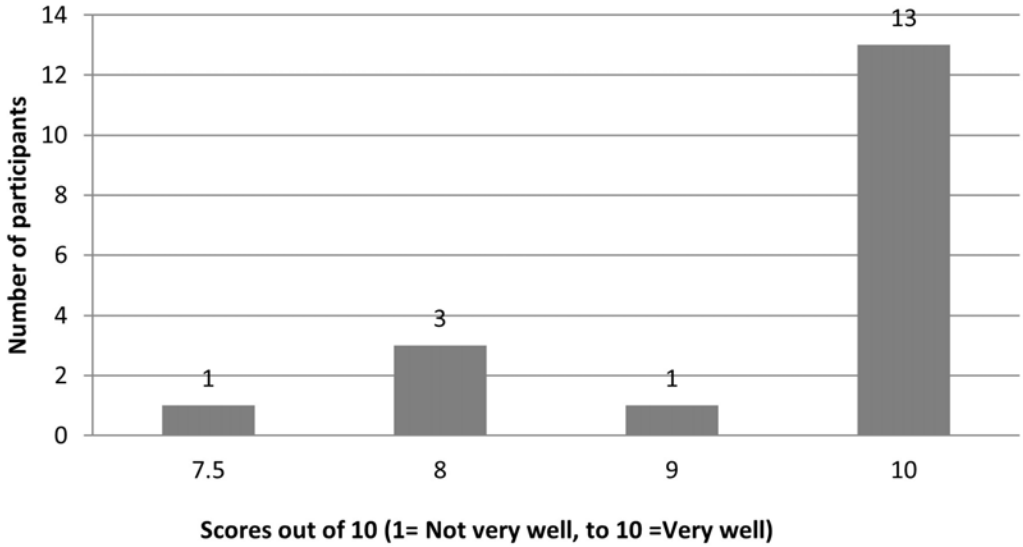
Characteristics	Pacific Island (n=7)	Māori (n=4)	NZ European (n=5)	Asian (n=2)	Total (n=18)
Preferred language by parents/caregivers					
English	5		5		10
Bilingual		4			4
Other	2			2	4
Age of parent/caregiver participating					
16–25yrs	1		2		3
26–35yrs	6	3	3	1	13
36–45yrs		1		1	2
Median number of children in each household (range)					
<12yrs	4 (1–4)	3 (1–4)	3 (2–5)	3 (2–4)	3 (1–5)
13–17yrs	0 (0–2)	1 (0–4)	0 (0–1)	0 (0–0)	0 (0–4)
>18yrs	3 (1–6)	2.5 (2–3)	2 (1–8)	3 (3–3)	2.5 (1–8)
Main caregiver of the sick child at home					
Mother	3	3	3	1	10
Mother & Father	4		2		6
Aunt & Grandmother		1			1
Mother, Father & Grandmother				1	1
Highest level of participant's education					
High school	4	2		1	7
Tertiary	3	2	5	1	11

Table 2: Type and frequency of discharge medicines information provided to parents/caregivers on their child's discharge from hospital and when filling prescriptions at community pharmacies.

Types of information provided to parents/caregivers (n=18)	Frequency item was provided by hospital staff (doctor or nurse) n (%)*	Frequency item was provided by community-pharmacy staff n (%)*
Type of medicine	12 (66.7)	5 (27.8)
Purpose of medicine	9 (50.0)	3 (16.7)
Dosing regimen (how much to give)	1 (5.6)	8 (44.4)
Frequency of dosing (how often to give)	0	2 (11.1)
Duration of the course	7 (38.9)	4 (22.2)
When to contact doctor	1 (5.6)	1 (5.6)
How to store medicine	0	4 (22.2)
To take prescription to pharmacy to fill and/or for more medicines information	3 (16.7)	0
To give with food or without food	1 (5.6)	1 (5.6)
Asked about or provided measuring equipment	0	1 (5.6)

Note *= percentage of maximal response (n=18).

Figure 1: How well parents/caregivers perceive they understand instructions on the medicine labels.



Understanding instructions

Participants were asked how well they understood the labelling instructions (to assign on a scale of 1= not very well to 10 = very well, see Figure 1). Seventeen (94%) of participants claimed to understand the instructions well/very well, scoring 8–10 on the scale.

Taste issues

Four participants found it difficult to administer antibiotics because of its taste; amoxicillin/clavulanic acid (2), amoxicillin (1), erythromycin (1). One participant said: "*erythromycin was horrible…it had a strong aniseed flavour*".

Dose measuring equipment

Participants were found to use different types of measuring equipment at home. The majority (13, 72%) used oral syringes, but some used two or more types of measuring equipment, depending on the circumstances (see Table 3). One participant claimed to use kitchen spoons.

Accessibility of measuring equipment

Parents/caregivers obtained oral syringes from hospital and/or community pharmacies. The oral syringes were supplied free of charge from the hospital, or parents/caregivers were charged a small fee ($1–$2) from community pharmacies. Some parents/caregivers used measuring equipment with faded or non-existent markings due to frequent use.

Ability to measure/calculate doses

One participant capably measured a 6.25mL dose of antibiotic using an oral syringe for a child under one year but used measuring spoons (with 2.5mL and 5mL volume sizes) for older children.

In contrast, one participant struggled to measure 6.8mL of paracetamol describing the dose as "*confusing*", and another was not able to measure 3.75mL of paracetamol. The latter thought "*it was a random number and quite hard to give [so] gave slightly less*".

Storage of medicines

Almost all participants (17, 94%) kept medicines requiring refrigeration (i.e., antibiotics) in the appropriate place and seven (39%) kept analgesics in the refrigerator as well. One participant did not have a refrigerator, so kept all medicines on a kitchen shelf. Analgesics not requiring refrigeration were kept in a variety of places, such as kitchen cupboards, on top of the refrigerator, in a medicine box or in the parent's bedroom.

Fifteen (83%) participants confirmed medicines were stored out of the reach of children. The other three stored medicines that could have been easily accessible to young children. In these cases, medicines were in an unlocked cupboard in the corridor, inside or on top of kitchen drawers.

Disposal of medicines

Nine participants (50%) disposed expired or unused medicines in general household rubbish

Table 3: Scenarios where parents/caregivers have used different types of measuring equipment at home to measure oral liquid medicines.

Number of parents/ caregivers using (n=18)	Different scenarios of parents/caregivers using different types of measuring equipment to measure oral liquid medicines
13	Oral syringes.
3	Oral syringe and a measuring cup. (One used oral syringe initially but when the volume got low in the medicine bottle, parent/caregiver poured liquid medicine into a measuring cup to measure dose. Another used a proprietary oral syringe available with Nurofen® suspension bottle bought from pharmacy.)
1	Proprietary measuring cup (available with Augmentin® suspension bottle dispensed by pharmacy) and kitchen spoon for liquid paracetamol.
1	Proprietary measuring cup (Augmentin ® suspension bottle), proprietary oral syringe (Nurofen® bottle), and a cylindrical measuring spoon to measure both antibiotics and analgesics.

Table 4: Types of discharge medicines information preferred by parents/caregivers (n=18).

What form of information preferred by parents/caregivers?	**n (%)***
Written	3 (16.7)
Verbal	2 (11.1)
Both written & verbal	12 (66.7)
Other	1 (5.6)
All	18 (100.0)
What language is preferred by parents/caregivers?	**n (%)***
English	13 (72.2)
English & own language	5 (27.8)
All	18 (100.0)
Specific Information about medicines?	**n (%)***
What is the medicine for?	16 (88.9)
How much medicine to give?	16 (88.9)
How to measure the medicine?	9 (50.0)
How to give the medicine in relation to food?	16 (88.9)
How often to give the medicine for?	15 (83.3)
How long to give the medicine for?	16 (88.9)
How does the medicine work?	12 (66.7)
What are the side effects of the medicine?	16 (88.9)
How much does the medicine cost?	9 (50.0)
Where to get the medicines from?	5 (27.8)

Note *= percentage of maximal response (n=18)**

whilst seven (39%) poured them down the sink. One did both, while another poured liquid medicines down the sink but flushed tablets down the lavatory. Only one participant knew that unused medicines could be returned to the pharmacy for disposal. Three participants stated that they would like the expiry date written on the dispensed medicine, so they would know when to discard.

Further information that parents would like to receive

Based on their experience, participants were asked what types of medicines information they would like to receive in future from a hospital, for their children, prior to discharge (see Table 4).

Most of the participants (72%) who wanted written information preferred to receive it in English, whilst 28% wanted written information provided in both English and their own language (Māori n=1, Samoan n=1, Tongan n=1, Chinese n=1 and Indian n=1). They stated: *"it will be good to be able to read it later, sometimes you forget" and "it is good in verbal [form] because they explain to you and it is also good to get on paper … because when you are in the hospital, you may be tired and exhausted and may not take … in all the information and remember it later"*.

Most (16, 89%) participants made no further attempts to obtain any more medicines information once they reached home.

Discussion

Parents and caregivers play an integral part in managing their children's medicines after hospital discharge. How well they are able to do this at home might depend on how well they are informed by the HCPs involved.

Medicine information requirements

This New Zealand based study found that HCPs provided variable types of medicines information when giving prescriptions to parents/caregivers of sick children at the time of hospital discharge. This is consistent with a UK study that found variable or inconsistent information was provided to parents by HCPs at paediatric diabetes outpatient clinics.[10]

The majority of participants showed a basic understanding of antibiotics and analgesics, and they did not seek any further information post-discharge. It is possible that they thought they were familiar with these medicines, satisfied with the information provided and/or unsure where or how to seek further advice.

Most importantly, the majority of parents/caregivers agreed that they would like specific medicines information when receiving a prescription for their child such as the indication or purpose of the medicine(s), their dose, frequency, administration in relation to food, duration of medicine course, accurate measurement, mechanism of action, possible side effects, and procurement costs. In addition, participants were unsure what to do about missed doses and how to dispose of medicines safely. These types of information needs concurred with earlier findings in Australia, where parents requested information on dose, administration, indication and adverse drug reactions.[11]

HCPs need to work together to consistently provide these important medicine information needs to parents/caregivers. They also need to adopt health literacy strategies to communicate easy to understand medication information[12] especially for our parents/caregivers from multicultural backgrounds.

Measuring equipment

The present study found that participants used a variety of devices for administering medicines. Unfortunately, over a quarter (28%) did not use the most accurate device, an oral syringe, but used a measuring cup and some of these had faded markings. A higher risk of dosing errors with parents using measuring cups has been previously reported.[7,13,14] A United States (US) randomised controlled study (n=2,099) found parents made more dosing errors with measuring cups than with oral syringes (adjusted odds ratio = 4.6; 95%CI, 4.2–5.1).[15] In total, 84% made one or more errors, 21% gave more than twice the prescribed dose and the error rate was much *higher* when *smaller* doses were prescribed.[15]

A US study based in a dental clinic found parents were more likely to accurately measure a dose 95% of the time when using an oral syringe or cylindrical measuring spoon, compared to 60% of the time with a medicine cup with black calibrations and 42% of the time when using one with clear calibrations.[16] Worryingly, in our study, parents only had access to medicine cups with clear calibrations so a greater margin of error was likely.

Our study found parents' perception was to use oral syringes for infants and measuring spoons for older children. This is consistent with the dental study where only a small proportion of participants [19% (n =23)] used oral syringes because "*their children were not infants*".[16]

Kitchen spoons were sometimes used by participants in the present study. These are not stan-

dardised measuring equipment and have a much greater margin of error than calibrated oral syringes.[6,7] One study of 30 parents found 20% used household spoons, all of whom measured doses incorrectly.[17] Fortunately, in our study, only one parent used a kitchen spoon. To prevent medication error, it would be advisable to provide parents with oral syringes at the time of discharge so that parents do not resort to using household spoons[13,18] or measuring cups.

In our study, some children were prescribed doses of up to two decimal points. Parents have been shown to have difficulty measuring doses such as 2.5mL, and 7.5mL.[15] Ideally, doses should either be rounded to the nearest whole number or parents/caregivers should be provided with oral syringes. Earlier studies[6,19–21] demonstrated that HCPs *need to show* parents/caregivers how to measure medicines accurately prior to discharge *and* provide measuring syringes clearly marked with the correct dose to avoid medication errors.

Cultural, language and low health literacy barriers could have impacted on the parents/caregivers' understanding of what HCPs expected them to do.[22] These factors, plus lack of appropriate dosing tools could contribute to liquid medication dosing errors in children by parents at home.[23] A study in the USA found parents with low health literacy and limited English proficiency were more commonly making dosing errors while measuring liquid medications.[23] A large proportion of our parents/caregivers from various ethnicities do not have English as their first language. Parents/caregivers with known low health literacy such as some Māori and Pacific peoples, [22] and those with low education levels,[12] such as some in the present study, would be more vulnerable to poor understanding and difficulties when following precise medication dosing instructions.

Storage and disposal of medicines

Appropriate and safe storage of medicines in homes can also help prevent or at least reduce the risk of unintentional overdose in children.[5,24] Most of our parents/caregivers were storing medicines appropriately. However, it is important to remind parents/caregivers to store medicines safely at home.

The very surprising finding of this study was the fact that the majority of parents/caregivers were not aware of the most appropriate method of disposing of unwanted medicines. Inappropriate disposal of medicines can cause environmental pollution while use of expired medicines can cause harm if administered to children due to medicine degradation resulting in toxicity or sub-therapeutic effect.[25] We suggest that HCPs and government bodies work together to increase medication safety awareness.

Recommendations

This study generates important information for quality improvement and a standardised paediatric discharge process is recommended to improve parents/caregivers understanding and management of their children's medications at home.[26] This discharge process will need to include the relevant HCPs including pharmacists[27] to work collaboratively and consistently using health literacy communication strategies such as (i) providing written medication information for better recall of information, (ii) using teach-back techniques to see if parents/caregivers have understood instructions, (iii) avoiding giving too much information all at once, (iv) using interpreters for those with a language barrier, and (v) providing measuring equipment for improved adherence and correct administration of medication at home.[12,26]

Limitations

This was a small study based in one centre so the results cannot be generalized widely across New Zealand or elsewhere. Participants with no English language skills and those with children having more complex medical conditions were excluded. These parents/caregivers would be a good target for future studies as health literacy, health system navigation and treatment complexity issues may have an impact on managing medicines.

All participants had more than one child and were familiar with liquid forms of paracetamol and various antibiotics. This could have influenced the results and made it difficult to determine the experience of the parents/caregivers not familiar with these medicines.

We did not examine how accurately participants measured liquid doses. Had this occurred, it would have produced more information around dosing errors and understanding of instructions.

Future studies

The findings from this study warrant further studies in this area. Firstly, a larger study, throughout New Zealand incorporating non-English speakers and/or more medically complex paediatric patients could be undertaken to find the medicine information needs for a wider group of parents/caregivers. Secondly, the clarity, comprehension/barriers to understanding of labelling instructions or any verbal and written medicine information provided needs to be examined.

Conclusion

This small New Zealand based study with parents/caregivers from various ethnicities showed variation in discharge medication education and information provided by HCPs to assist them to manage their children's medicines at home.

While the majority of parents/caregivers had a reasonable understanding of antibiotics and analgesics use, they lacked appropriate measuring equipment and knowledge on how to measure liquid medicines accurately, and on the safe storage and disposing of medicines at home. A significant proportion of parents/caregivers were not provided with oral syringes, which could have adversely affected their child to receive correct doses of medicines at home. The study provides useful information for quality improvement and future training of all the HCPs involved in a discharge process. HCPs must ensure they provide, using a health literacy lens, appropriate and consistent information on medications, medication equipment free of charge, plus education and training on administration instructions, so that parents/caregivers can manage medicines well at home after their child's discharge from hospital.

COMPETING INTERESTS
Nil.

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Appendices

Appendix 1: Interview questionnaire.

(NOTE: The interviewer may re-phrase the question if more explanation is needed).
Part A: Demographics (During admission)

1. What ethnic group do you belong to?

- European
- Māori
- Pacific Peoples*
- Asian*
- Middle Eastern/Latin American/African
- Other Ethnicity
  *Please state which sub-group you belong to e.g. Samoa/Indian

2. What language do you prefer to speak most of the time?

- English
- Both English and another language (please state other language)
- Other language only (please state other language)

3. What age group do you belong into?

- 16 to 25 years
- 26 to 35 years
- 36 to 45 years
- >45 years

4. How many adults and children live in your household?

- Children (≤12 years)
- Adolescents (13-17 years)
- Adults (≥ 18 years)

5. Who looks after your child's medicines at home? (Tick more than one if needed.)

- Mother
- Father
- Grandparents
- Siblings
- Caregiver
- The child themself (please specify age)
- Others (please specify)

6. What is the highest education level of the main caregiver(s) administering and looking after medicines for your children?

- No school
- Below high school
- High School

- Tertiary qualifications
- Other (please specify)

Part B: Post discharge (2 to 3 days after discharge)

7. Who gave you the prescription before discharge?

- Nurse
- Doctor
- Other (please specify)
- Don't remember
- Don't know

8. Were your child's medicines explained to you before discharge?

- Yes
- What information was given?
- No
- Don't remember
- Comments

Medicine		Reason for medicine	Type of medicine	When to take it?
1	Yes	Specify details in here		
	No			
2	Yes			
	No			

9. Have you picked up the medicines from a pharmacy?

- Yes
- No
- If No, then can they explain why this has happened?

10. Were your child's medicines explained to you when you picked them up from a community pharmacy?

- Yes
- What information was given
- No
- Don't remember
- Comments

11. Were your child's medicines explained to someone else who may have picked them up for you from a community pharmacy?

- Yes
- What information was given
- No

- Don't remember
- Comments

12. Have you sourced information about these medicines from anyone or anywhere else?

- Internet
- GP
- Community support group
- Plunket
- Family or *whānau*
- Other (please specify)

13. Has your child started taking the medicines?

- Yes
- No
- If No, then can they explain why this happened?
- Comments

Part C: Post discharge (2 to 3 days after expected completion of antibiotics course)

14. Is your child still taking any medicines?

- Yes
  Which ones
  Why is that?
- No
  Which ones
  Why is that?

15. What do you use to measure liquid medicines?

- Medicine measuring spoons
- Oral Syringe
- Medicine measuring cups
- Don't have any medicine measuring cups/syringes/spoons and use;
  - Kitchen spoons
  - Drinking cups/glass
  - Other (please tell me/show me)

16. Where do you store medicines at home (Tick more than one if needed)?

- Fridge
- Cupboard
- Out of reach of children
- Bathroom
- Other place (please specify/show)

17. How long do you keep your medicines for?

- Until the course finishes
- Until the medicine expires
- Other (please specify)

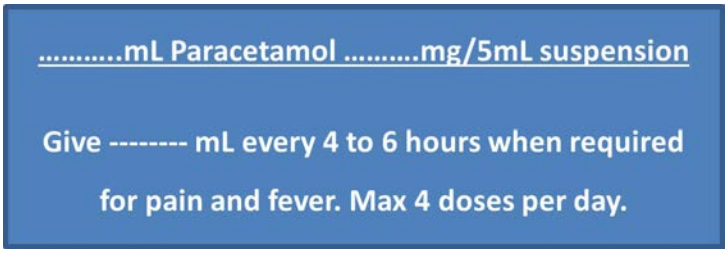
18. How do you discard expired or unwanted medicines?

- Return them to the pharmacy
- Put them down the sink
- Put them down the toilet
- Put them in the rubbish bin
- Other (please specify)

19. How well do you understand the instructions on the labels?

1 2 3 4 5 6 7 8 9 10
Not very well Very well

Appendix Figure 1:



(*Interviewer shows the participant this label, completed with the child's dosing instructions given by doctor on prescription and given by community pharmacy)*

20. What is this medicine for?
21. How do you measure the volume? Please can you show me?

Appendix Figure 2:

*Antibiotics that are commonly prescribed for cellulitis are flucloxacillin, cephalexin, amoxicillin/clavulanic acid and erythromycin.

22. How long are you going to give this medicine for?

(Interviewer shows the participant this label, completed with the child's specific antibiotic, dosing instructions given by doctor on prescription and given by community pharmacy)

23. What is this medicine for?
24. How many days did you give this medicine for?
25. Have you had any difficulties with any of these medicines?

- No
- Yes (please specify)

These questions below are about what type of information you would like to receive prior to your child's discharge from hospital.

26. In what form would you like to receive any information about your child's medicines in?

- Written information
- Verbal information
- Both written and verbal information
- In pictures (please specify type e.g. times of the day, number of spoonfuls)
- Audio-visual recording (e.g. television)
- Other (please specify)

27. What language would you like to receive information about your child's medicines in?

- English
- Your own language (please specify)

28. What information would you like on discharge about your child's medicines (Tick more than one if needed)?

- What the medicine is for?
- How much medicine to give?
- How to measure the medicine?
- How to give the medicine in relation to food?
- How often to give the medicine?
- How long to give the medicine for?
- How does the medicine work?
- What are the side effects of the medicine?
- How much does the medicine cost?
- Where to get the medicines from?
- Other (please state)

Defining rural in Aotearoa New Zealand: a novel geographic classification for health purposes

Jesse Whitehead, Gabrielle Davie, Brandon de Graaf, Sue Crengle, David Fearnley, Michelle Smith, Ross Lawrenson, Garry Nixon

ABSTRACT

AIM: Describe the first specifically designed and validated five-level rurality classification for health purposes in New Zealand that is both data-driven and incorporates heuristic understandings of rurality.

METHOD: Our approach involved: (1) defining the purpose and parameters of a proposed five-level Geographic Classification for Health (GCH); (2) developing a quantitative framework; (3) undertaking co-design with the National Rural Health Advisory Group (NRHAG), and extensive consultation with key stakeholders; (4) testing the validity of the five-level GCH and comparing it to previous Statistics New Zealand (Stats NZ) rurality classifications; and (5) describing rural populations and identifying differences in all-cause mortality using the GCH and previous Stats NZ rurality classifications.

RESULTS: The GCH is a technically robust and heuristically valid rurality classification for health purposes. It identifies a rural population that is different to the population defined by generic Stats NZ classifications. When applied to New Zealand's Mortality Collection, the GCH estimates a rural mortality rate 21% higher than for residents of urban areas. These rural–urban disparities are masked by the generic Stats NZ classifications.

CONCLUSION: The development of the five-level GCH embraces both the technical and heuristic aspects of rurality. The GCH offers the opportunity to develop a body of New Zealand rural health literature founded on a robust conceptualisation of rurality.

How rurality is defined matters, both from a policy and service delivery perspective, and for rural populations and communities.[1] In health contexts a fit-for-purpose definition permits the accurate monitoring of the health of rural populations. This may identify rural–urban health inequities, providing the impetus for targeted strategy, policy, and interventions for the equitable allocation of resources.[2–6] However, no internationally agreed definition of "rural" exists. Definitions are context-dependent, change over time, and have become increasingly blurred.[1] To date, Aotearoa New Zealand has lacked a rural–urban classification designed for use in health research and policy.

Defining "rural"

Geographers have long contested rurality definitions.[7] The two main approaches to conceptualizing and defining rurality are: (1) socio-cultural; and (2) descriptive and data-driven.[8] Socio-cultural approaches assess cultural characteristics of communities to define places as rural or urban.[9] Descriptive approaches employ technical and quantitative methods to empirically describe socio-spatial characteristics to classify places according to pre-defined criteria.[8] Both approaches have limitations, particularly when used alone. Socio-cultural approaches assume that population density affects behaviour, and that values and behaviours differ between rural and urban residents, despite contradictory evidence.[8] Conversely, descriptive approaches are strongly critiqued as providing an inadequate view of the social construction that is rurality.[1,10,11] They also claim a clear geographic distinction between rural and urban areas, when in fact borders are often blurred, contested, and subjective.[11]

The core concepts and measures of rurality—population size and proximity to metropolitan areas—have remained consistent since the 1970s.[1] In the United States of America, there are five key measures of rurality for epidemiological studies, all based on a combination of population size, density, and distance or commuting patterns.[12] Canada has at least four different rurality classifications used in health research—all based on a combination of population size, density and distance.[13] While exact thresholds cannot be univer-

sally applied, factors of population size, density, and distance are key considerations in international geographic classifications of rurality. There is also growing recognition of "rurality" as a fluid, context-dependent, concept[1] that is socially constructed and defined by discourse.[8] People construct themselves as *being* rural, and rurality is in the eye of the beholder.[8] A meaningful classification of rurality must therefore effectively balance "technical" and "discourse" approaches. The United States Rural Policy Research Institute[14] offers guidance on developing rurality classifications for health. It acknowledges that a transparent data-driven geographic approach is preferred to intuition or personal experience, especially in research and policy contexts where quantitative measures are needed to consistently define populations or designate policies.[1] However, a purely technical approach may not produce the most fit-for-purpose classification of rurality—a concept which is multifaceted and nuanced.[1,7–9] Geographic approaches must therefore be combined with qualitative evaluation and "ground truthing" to ensure the final classification has face validity. Overall, classifications must derive from a clear, transparent, and replicable process, and must also make sense on the ground.[9]

Defining rural in the New Zealand health context

The definition of rurality is an essential component of research exploring rural–urban health disparities. Such disparities, that intersect with and exacerbate the observed disparities associated with deprivation and ethnicity, have been well described internationally,[15–17] but not as clearly demonstrated in New Zealand. Health practitioners, academics, and other informed stakeholders argue that this is due to the different definitions of "rural" used. These result in inconsistent categorisation of areas and populations, impacting the results of epidemiological studies and health service research, and thereby potentially masking inequities.[18–23] This is an example of the influence of aggregation methods,[24] and the Modifiable Area Unit Problem (MAUP), which highlights that the results of analysis can vary according to the size, number, and configuration of spatial units that are used.[25] The choice of rurality classification also influences results, as different classifications aggregate together different populations into rural or urban categories.

Over two decades, more than 30, usually generic, definitions of rurality have been used in New Zealand health research.[26] The Statistics New Zealand (Stats NZ) Urban Rural Experimental Profile (UREP)[27] is commonly used but may have produced misleading results. The UREP breaks New Zealand into three urban and four rural categories, as follows.

Urban areas:

- Main urban areas—populations of 30,000 and above
- Satellite urban areas—populations between 1,000 to 29,999, where 20% or more of the working population works in a main urban area
- Independent urban communities—populations between 1,000 to 29,999, where less than 20% of the working population works in a main urban area.

Rural areas with populations of fewer than 1,000 people were classified into the following categories based on census commuting data between home and work addresses:

- Rural areas with high urban influence
- Rural areas with moderate urban influence
- Rural areas with low urban influence
- Highly rural/remote areas.

In 2010, the National Health Committee found little rural–urban difference in health outcomes,[28] a conclusion that is likely an artefact of how the UREP was used in their analysis.[29] In particular, "Independent urban communities" could be more appropriately considered as rural, while "Rural areas with high urban influence" are better classified as urban. Modifying the UREP, to better represent rural health understandings of "rural", increased the relative incidence of rural heart disease from 62% to 166% of the urban incidence.[28–30] In 2018, Stats NZ updated its Statistical Standard for Geographic Areas (SSGA18),[31] creating Statistical Area 1s (SA1s) as the smallest output geography for census population data. In 2020, Stats NZ's Urban Accessibility (UA) classification[32] replaced the UREP. The UA was designed to recognise the impact that proximity to urban centres has when determining gradations of rurality. However, the UA remains a "generic" classification that was not specifically designed for health outcome analyses. Complexities around rural and urban fringes,[11] as well as thresholds between categories, have not been considered from a health perspective. The UA, therefore, has the potential to continue masking rural–urban health inequities.

There has been a pressing need for a rural–urban classification which supports the consistent analysis of national health data. As the Minister of Health,

Andrew Little, noted in his keynote address at the 2021 NZ National Rural Health Conference,[33] the definition of rural is "not just semantic" and has real implications in terms of policy decisions and resource allocation. Poorly defined rural–urban divisions lead to poorly defined and implemented policies.[1] The objective of this paper is to develop and validate a Geographic Classification for Health (GCH) that is not only descriptive and technically robust for use within policy and research contexts, but also aligns with a heuristic sense of what is understood to be rural in the New Zealand health context.

Methods

A mixed-methods approach to co-designing and developing a five-level GCH was used. All areas of New Zealand were classified into five categories, two urban (U1 or U2) and three rural (R1, R2, or R3). To determine appropriate thresholds and develop a fit-for-purpose geographic classification of rurality, key criteria outlined in the international literature were examined.[14,34–36] The key criteria and details of how these were addressed in the development of the GCH were previously described[37] and are available as supplementary material (Appendix 1).

Key steps

The development, testing, and use of the GCH outlined in this paper followed five key steps (Figure 1). The key co-design partners in developing the GCH were the Ministry of Health's (MoH) National Rural Health Advisory Group (NRHAG), whose members include representatives of the MoH, the New Zealand Rural General Practice Network (NZRGPN), Rural Health Alliance (RHANZ), Primary Health Organizations (PHOs), District Health Boards (DHBs), the Royal NZ College of General Practitioners (RNZCGP) and rural Māori healthcare providers.

Step 1: defining the purpose and parameters of the GCH

The purpose and parameters of the GCH were discussed and finalised among the research team and our co-design partners, NRHAG.

Step 2: developing a quantitative framework for the GCH

A transparent quantitative model was developed based on high quality data and clear criteria from key rural health documents and research.[28,38–40] Engagement with MoH and Stats NZ indicated that using the "building blocks" of the UA (SA1s, population size, and drive time) as the foundation for the GCH would improve its uptake and utilisation. This is because the work undertaken by Stats NZ during the SSGA18 Review[31] and development of the UA[32] followed international best practice, was detailed and robust, and underwent rigorous testing. Furthermore, SA1s are the smallest geographic unit that census-based data, such as population counts, ethnicity and area-level socio-economic deprivation, are made available. Producing the GCH at the SA1 level ensures compatibility with other important datasets that use SA1s.

The UA uses population and drive time thresholds to classify each SA1 into one of eight gradations of urbanicity that can be aggregated to a binary rural–urban variable. Towns and cities with a population of 10,000 or more, are classified into three categories depending on population size: major (≥100,000), large (30,000–99,999) or medium (10,000–29,999) urban areas. All other SA1s are assigned one of five levels of urban accessibility ranging from "high" to "very remote" depending on the travel time to the edge of an urban area, as detailed in Table 1.

To develop the GCH, important modifications to the above population size and drive time thresholds were made through co-design workshops with NRHAG and consultation with stakeholders. Particular consideration was paid to the New Zealand health context, including principles such as the agreement between the MoH and PHOs for 24-hour primary care[39] and the "Golden Hour".[38]

Step 3: qualitative validation

Extensive consultation was undertaken with key stakeholders between March 2020 and February 2021. This involved both face-to-face and virtual seminars and workshops with more than 20 organisations and over 300 individuals from a range of sectors. Participants included likely end-users of the GCH—such as health researchers, policymakers, and organizations involved in the delivery of health services—as well as representatives of rural communities and health professional groups. Seminars and workshops involved an explanation of the GCH's purpose, the methodology and framework used to develop it, the generic UA, and proposed versions of the GCH (which were modified iteratively throughout the consultation period). Attendees identified their preferred classification and provided feedback on the framework and methodology used to develop the GCH.

Step 4: testing the validity of the GCH

In addition to the qualitative validation described in step 3, quantitative assessment was undertaken to determine the ability of the GCH to accurately classify patients enrolled in urban and rural general practices was compared to the UA and UREP. Although travel for primary healthcare is complex,[41] it can be assumed that most patients living in urban areas enrol with urban GP practices, and most patients living in rural areas likewise enrol with rural clinics. For funding purposes, local rural service alliance teams (composed of local community and primary care provider representatives) are responsible for identifying rural practices in their region. Based on criteria in the Rural Ranking Scale[42,43] and local knowledge, and through considerable consultation, local formulae are developed to allocate rural funding. Two PHOs that had successfully completed this process, Mahitahi Hauora and WellSouth, provided anonymised patient enrolment data and a list of the urban or rural funding status of all practices in their region. This was used to determine whether patients enrolled in rural practices were living in rural locations. Comparisons were undertaken to estimate how well the UREP, UA, and various versions of the GCH aligned with PHO enrolment-based rurality. The "accuracy" of each classification was calculated as the percentage of patients for whom the binary urban/rural indicator matched the urban–rural indicator in the PHO enrolment data; 95% Confidence Intervals (CIs) are provided for each accuracy estimate.

Step 5: describing rural populations and identifying differences in health outcomes

The GCH, UA, and UREP classifications were applied to the usually resident Census 2018 population to describe the "rural" population of New Zealand. Detailed examination of rural–urban differences in a range of health outcomes will be presented elsewhere. To provide an indication of the impact of different classifications, crude mortality rates for urban and rural residents were calculated using the GCH, UA, and UREP. Incidence rate ratios (IRRs) that compare, on a relative scale, the mortality incidence rate for rural residents with that for urban residents are provided with 95% CIs.

Ethics

Ethical approval for this research was obtained from the University of Otago Human Research Ethics Committee (reference number HD19/069), and consultation was undertaken with the Ngāi Tahu Research Consultation Committee.

Results

Purpose

The five-level GCH, a geographic classification with two urban categories (U1, U2) and three rural categories (R1, R2, R3) was developed for the purpose of accurately monitoring rural–urban differences in health outcomes.

Co-design and qualitative validation

When presented with the approach behind the GCH, participants stated that the GCH methodology was robust, and indicated that the GCH was an appropriate classification for their region. Participants often had in-depth local knowledge of their regions, and they could rapidly determine which of the versions "made the most sense on the ground".

Quantitative validation

Using the PHO enrolment data as the gold standard, the accuracy of the UREP was estimated to be 70.3% (95%CI 70.2%, 70.5%) for WellSouth patients, and 65.8% (95%CI 65.5%, 66.0%) for Mahitahi patients. In comparison, the accuracy of the UA was higher (WellSouth: 80.8% (95%CI 80.6%, 80.9%); Mahitahi: 81.3%, (95%CI 81.1%, 81.4%)), while the accuracy of the GCH was higher still (WellSouth: 94.7%, (95%CI 94.6%, 94.8%); Mahitahi: 92.5%, (95%CI 92.3%, 92.6%)).

The Geographic Classification for Health

The final population and drive-time thresholds used in the GCH are outlined below in Table 2. Through qualitative validation, five locations were identified as "special cases". Details of border issues and additional considerations are provided in the Appendices (Appendix 2). These cases will be reviewed with future updates to the GCH. Figure 2 and Figure 3 show the GCH for the North and South Islands of New Zealand, respectively.

Describing rural populations

Table 3 displays the New Zealand usually resident Census 2018 population classified as rural or urban under the GCH, the UA, and UREP. The rural–urban distribution of age, sex, and ethnicity is also displayed. Figure 4 highlights the overlap between how these populations are classified by each rurality classification. Appendix 3 includes a breakdown of the population overlap between each of the five GCH levels and rural–urban categories in the UA and UREP. It indicates that U1 and R3 have significant overlap with the urban and rural categories, respectively, in the UA and UREP. There are less similarities between the three clas-

Figure 1: Key steps in developing, testing, and using the GCH.

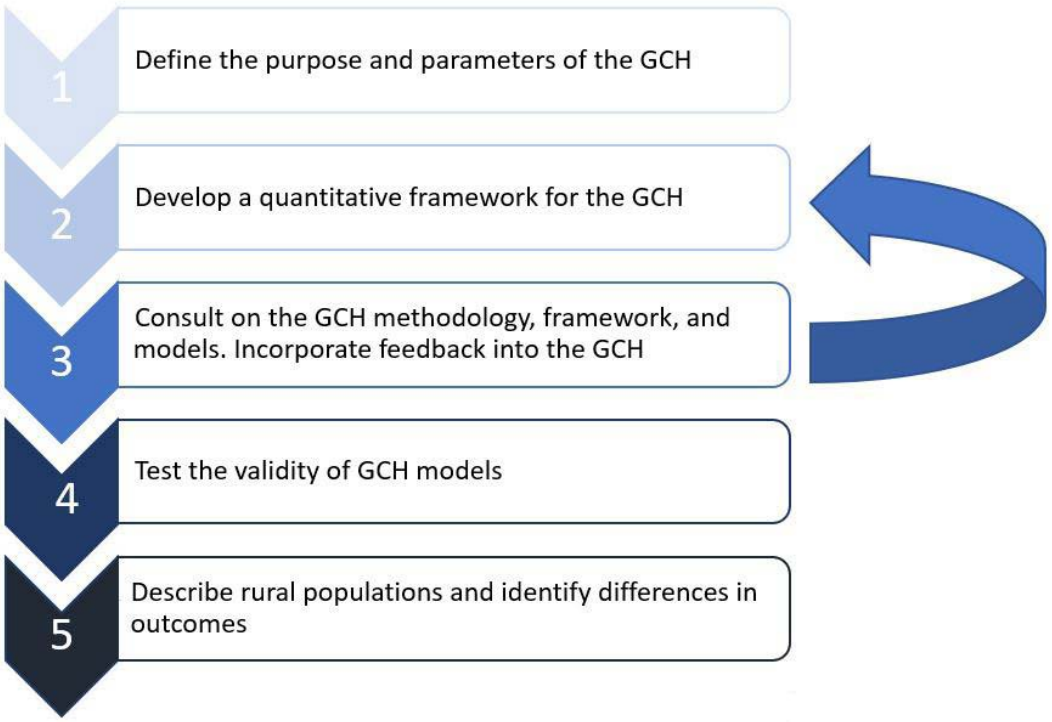


Table 1: Population and travel time thresholds used in the UA.

SSGA18 Urban Category	The Statistics New Zealand Urban Accessibility Classification				
	High Urban Accessibility	Medium Urban Accessibility	Low Urban Accessibility	Remote	Very Remote
Major urban (Population ≥100,000)	0–15 min	16–25 min	26–60 min	61–120 min	>120min
Large urban (30,000–99,999)		0–25 min	26–60 min	61–120 min	>120min
Medium urban (10,000–29,999)		0–15 min	16–60 min	61–120 min	>120min

Table 2: Population and travel time thresholds used in the GCH.

SSGA18 Urban Category	Geographic Classification for Health				
	Urban		Rural		
	Urban 1 (U1)	Urban 2 (U2)	Rural 1 (R1)	Rural 2 (R2)	Rural 3 (R3)
Major urban (Population ≥100,000)	≤25 min		>25–≤60 min	>60–≤90 min	>90 min
Large urban (30,000–99,999)		≤20 min	>20–≤50 min	>50–≤80 min	>80 min
Medium urban (10,000–29,999)			≤25 min	>25–≤60 min	>60 min
Small urban (1,000–9,999)				≤25 min	>25 min

Table 3: The population of New Zealand defined as rural or urban according to the GCH and two generic rurality classifications.

Population variable			GCH						% Rural		
		Total (n)	U1	U2	R1	R2	R3		GCH	UA	UREP
Total (n)		**4,699,188**	**2,961,138**	**845,169**	**570,147**	**266,928**	**55,806**		**19%**	**26%**	**15%**
			(col%)	(col%)	(col%)	(col%)	(col%)				
Age (years)											
0-14		922,791	19%	20%	19%	20%	20%		19%	27%	15%
15-29		962,919	23%	18%	16%	16%	15%		15%	20%	11%
30-44		903,750	21%	17%	17%	16%	16%		16%	23%	13%
45-59		932,628	19%	20%	21%	21%	22%		20%	30%	18%
60-74		673,122	12%	16%	18%	20%	20%		25%	33%	18%
75+		302,247	6%	8%	8%	8%	5%		23%	26%	11%
Sex											
Male		2,318,970	49%	49%	50%	50%	52%		19%	27%	15%
Female		2,379,873	51%	51%	50%	50%	48%		19%	26%	14%
Ethnicity											
European		3,297,183	64%	79%	83%	80%	74%		22%	31%	18%
Māori		775,626	13%	23%	19%	26%	32%		25%	33%	16%
Pacific		381,618	11%	4%	3%	2%	3%		7%	8%	4%
Asian		707,610	21%	6%	4%	4%	3%		5%	7%	3%
MELAA		70,632	2%	1%	1%	1%	1%		10%	10%	6%
Other		57,951	1%	1%	1%	1%	1%		20%	29%	17%

sifications for the populations defined as R1 and U2, indicating that this is where the GCH is most "novel" in its classification of rurality.

Differences in health outcomes

Crude all-cause mortality rates vary at each level of the GCH, but they are lowest in U1 and highest in U2 (Table 4). Rural–urban incidence rate ratios (IRRs), with U1 as the reference, suggest consistently higher mortality rates in rural areas, particularly R1 and R2. At the binary rural–urban level all-cause mortality rates and associated rural–urban IRRs also vary considerably depending on the classification used. Using UREP, the IRR estimates the mortality rate for rural residents at 67% that of urban residents whereas the GCH estimates the rural mortality rate as 21% higher than for urban areas.

Discussion

Statement of principal findings

The five-level GCH is a novel rurality classification which delineates three levels of rural and two urban levels for New Zealand health research and policy purposes. It evolved from extensive qualitative and quantitative development and testing and as such "makes sense on the ground" while being technically robust for use within policy and research contexts. It meets the key criteria for developing rurality classifications that have been described in the literature.[14, 34–36] Importantly, the GCH aligns with a both heuristic sense of what is rural in a health context, and understandings of rurality as evidenced by primary care enrolments.

When applied to 2018 Census data, the GCH describes a rural population which is substantially different from that defined by the UREP and UA classifications. Overall, 19% of the population—close to 900,000 people—are classified as rural by the GCH. This proportion is higher than the UREP (15%) because relatively large towns such as Taupō are appropriately reclassified from "Independent Urban Communities" to rural areas. The UA identifies an even larger rural population (26%). However, this is an inappropriate artefact resulting from the "High Urban Accessibility" peri-urban zone on the fringes of cities being classed as rural in the UA taxonomy. There is little direct overlap between the GCH, UA and UREP, and less than one-tenth of the population was classified as rural under all three of the classifications. While the population living in R3 areas is most consistently defined as rural, the R1 category has least overlap with "rural" in other classifications. In fact, there are around half a million people classified as urban by the GCH who would be considered rural under the UA or UREP.

The different rural populations described by the GCH, UA, and UREP are likely to have different health characteristics, as evidenced by higher rural mortality rates under the GCH. Our initial findings indicate that in New Zealand mortality rates are higher in rural areas as has been demonstrated in international contexts. They also suggest that previous classifications may have masked rural–urban differences in health outcomes. The fit-for-purpose definition of rurality provided by the GCH may contribute to uncovering other rural–urban variations in health outcomes.

Strengths and limitations of the study

Our development of the GCH shows that mixed methods can be used to design, develop, and test a technically robust and heuristically valid rurality classification that is not only useful in policy and research settings, but also reflects on-the-ground understandings of rurality. To our knowledge, this paper is the first to describe a mixed methods approach to developing a geographic classification of rurality for health research and policy purposes. Limitations include that we were unable to quantitatively validate the five "sub-categories" of the classification. The state of rural health research and data in New Zealand is still developing, particularly compared to other countries. As a result, New Zealand does not have large datasets, such as that used to validate the Modified Monash Model in Australia, that can be used to validate the GCH. Instead, the best available PHO data was used to validate the "binary" rural–urban categorisation. However, when considered in its entirety this paper outlines the case for a valid rurality classification that: has been purpose designed for health; has been quantitatively validated against PHO data; has been qualitatively validated through ground-truthing; describes a distinct rural population; and provides data that aligns with international findings of higher mortality rates in rural populations, and a rural–rural mortality gradient. The GCH is not only a novel and significant contribution to rural health research in New Zealand, but it will help to lay the foundations for improved quality and quantity of rural health research. By demonstrating that rural–urban disparities do in fact exist this work justifies a more thorough examination of the rural context.

Figure 2: Distribution of GCH categories for the North Island.

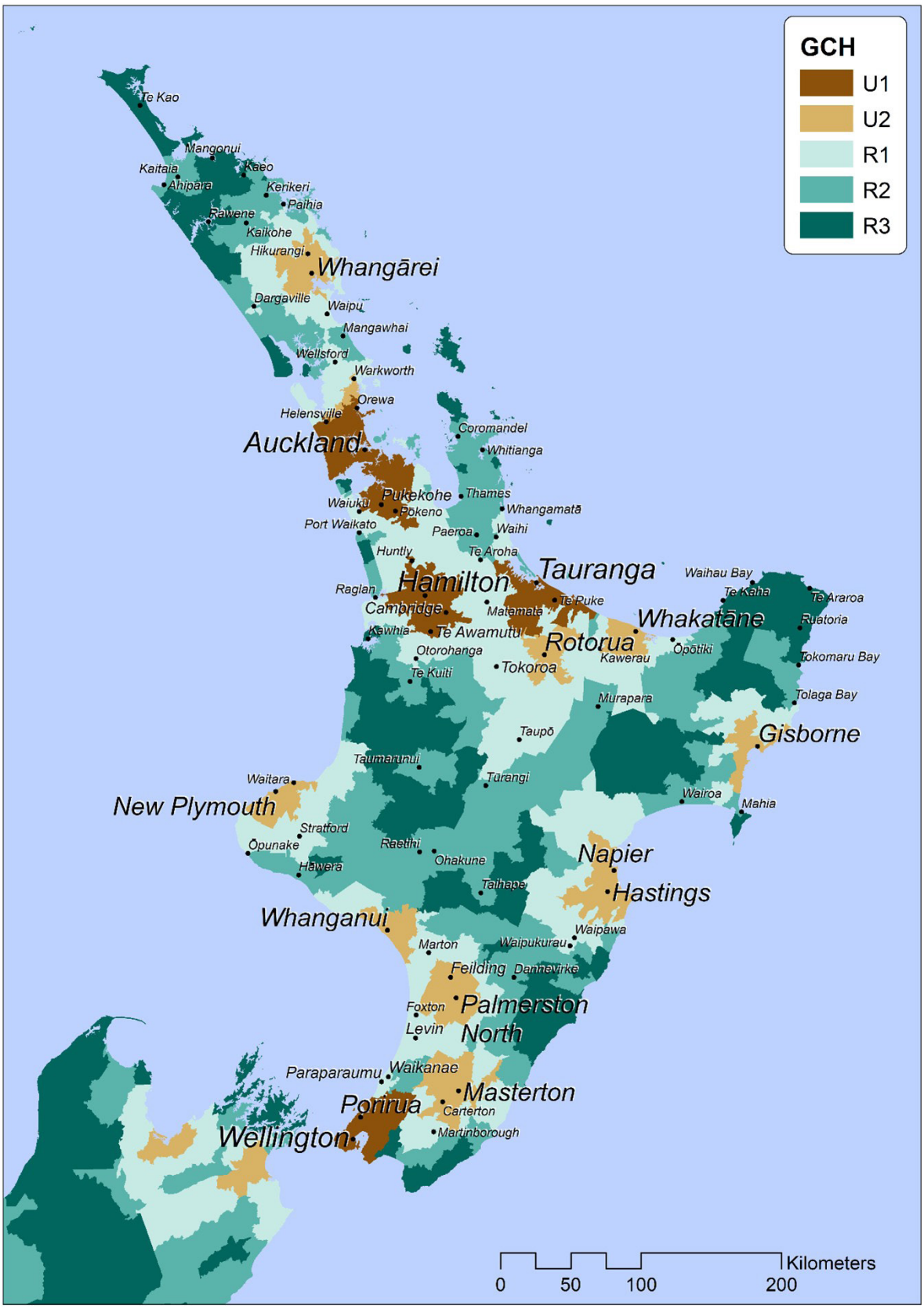
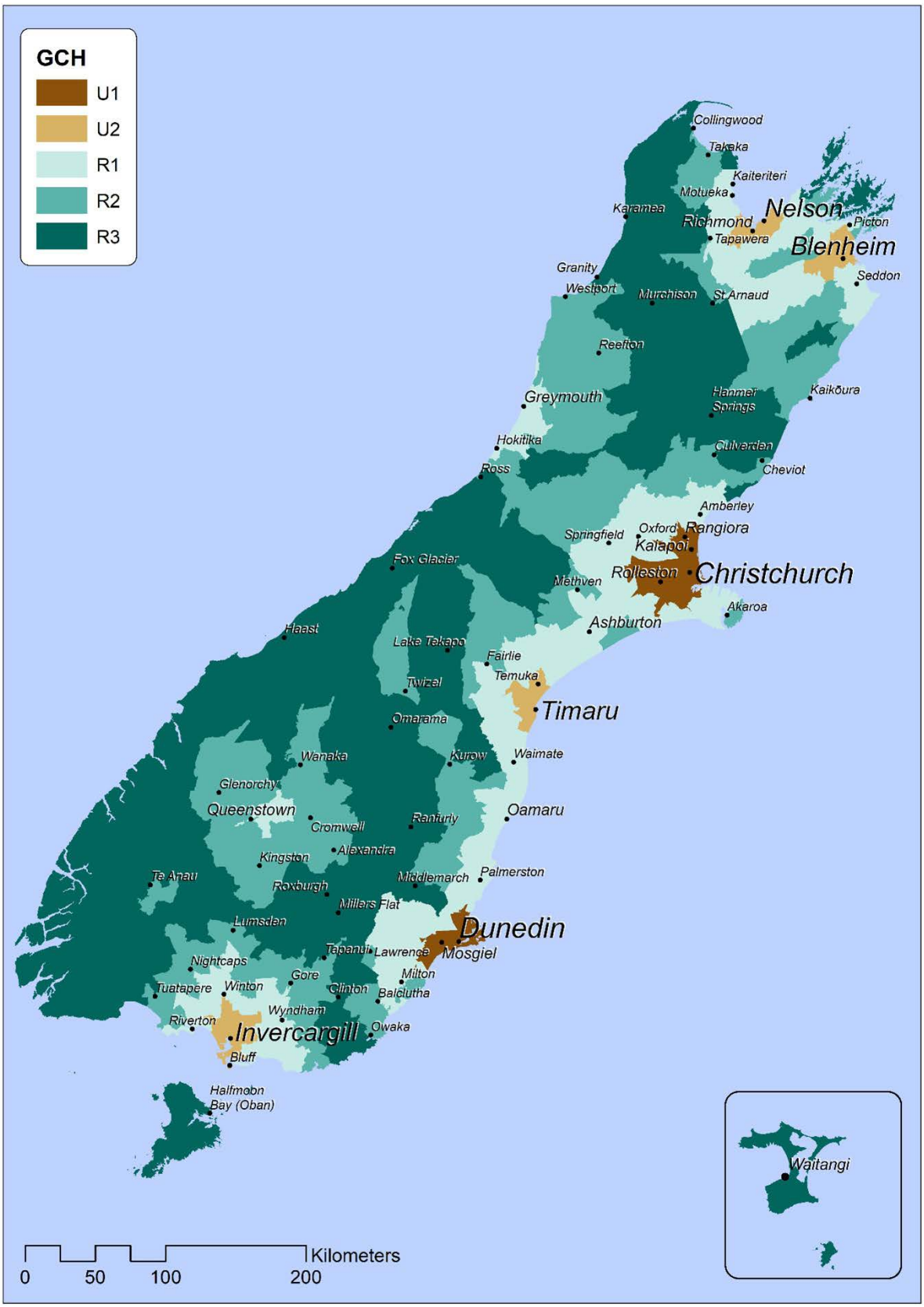


Figure 3: Distribution of GCH categories for the South Island.



Implications for policy-makers

The differences between rural populations defined using different classifications have research and policy implications, and highlight the importance of selecting an appropriate classification in health research or policy contexts. Uncritically selecting a classification, which may not have been designed to address the research question or policy issue, could produce misleading results and/or perverse policy outcomes. Researchers and policy makers need to understand the details and concepts behind rurality classifications used in previous health research when drawing conclusions and developing policy. Transparency in the development, selection, and use of rurality classifications is essential to ensure that the results of health research can be meaningfully compared over time. Since the GCH has been specifically designed and validated for health research and policy purposes, we argue that the GCH is likely to be more appropriate than generic alternatives in most health research and policy contexts. Inconsistent definitions of rurality in New Zealand health research have hindered understandings of rural health outcomes, subsequently limiting the development of specific rural health policies and interventions. Different classifications identify different "rural" populations, which has important implications for health policy and funding. These populations will have distinct health needs and require different services. While the GCH can describe a population as rural, it has not been designed to uncritically guide health policy and funding decisions. It is not a formula for distributing health resources or funding, nor is it an index of healthcare accessibility or workforce

Figure 4: The 2018 usually resident population defined as rural by the GCH, UA, and UREP.

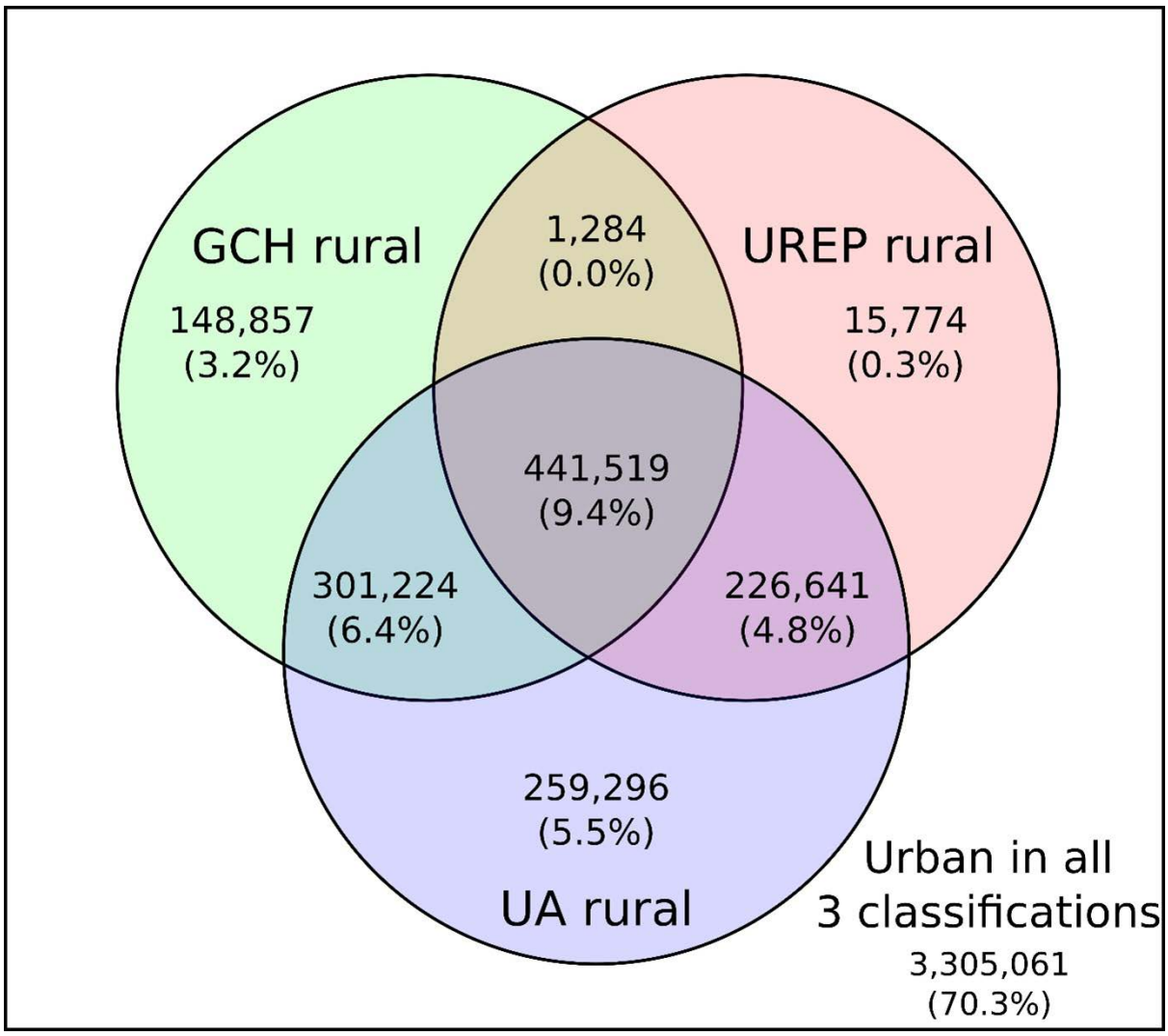


Table 4: Crude all-cause mortality rate per 100,000 people for rural and urban areas of New Zealand.

Classification		Mortality rate*	Incidence rate ratio	
			Est.	95%CI
GCH				
	U1	636	(ref)	
	U2	935	1.47	(1.45,1.49)
	R1	860	1.35	(1.33, 1.37)
	R2	863	1.36	(1.33,1.39)
	R3	699	1.10	(1.05, 1.15)
Binary categorisation				
GCH				
	Urban	703	(ref)	
	Rural	851	1.21	(1.20, 1.23)
UAC				
	Urban	722	(ref)	
	Rural	668	0.93	(0.92, 0.93)
UREP				
	Urban	743	(ref)	
	Rural	498	0.67	(0.66, 0.68)

*Crude all-cause mortality rate per 100,000 person-years (2013-2017)

shortage. Users must be aware of the limitations of a purely *geographic* classification of rurality. Additional data and local knowledge are crucial when making policy or funding decisions. This could include: the distribution of population subgroups; the locations of health services and workforce shortage; and the distribution of the social determinants of health.[44]

Future research

Although the GCH is designed to be stable over time, it needs to respond to major population changes and the way in which healthcare is delivered to rural communities. To ensure the GCH remains robust and relevant, our intention is to update it with the release of new census data. The same mixed method approach using data thresholds and qualitative validation will be followed. It is likely that in the next 10–15 years the GCH will remain largely stable, with some minor variation due to population fluctuations or changes in travel times. However, if the current health reforms result in major shifts in the geographic organisation of healthcare it may be necessary to review the "special cases" and the population and drive time thresholds used to delimit the GCH categories sooner than anticipated. We foresee the GCH as being a useful tool in health outcome analysis and hope that the results of future research will guide the development of comprehensive, evidence-based rural health policy in New Zealand.

Conclusion

This paper outlines a novel approach to developing a rurality classification for health that embraces both the technical and heuristic aspects of rurality. The development of the GCH is the first component of a wider Health Research Council of New Zealand funded project, the second phase of which will extend this work by analysing a range of health outcomes by rurality identifying whether rural–urban differences have previously been masked by generic classifications.[37]

COMPETING INTERESTS
Nil.

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Appendices

Appendix 1: Key concepts and criteria for developing rurality classifications.

Concept	Key criteria. The GCH should:	Action or consideration in GCH
Objectives & purpose	1) Have clear objectives and purpose	The GCH is intended to be a "fit-for-purpose" urban-rural classification for Aotearoa New Zealand health research and policy that accurately monitors urban-rural variations in health outcomes.
	2) Measure something explicit and meaningful	
Framework indicators & data	3) Be based on a framework or formula relevant to the purpose	Quality population data, stability, and an ability to update in response to five-yearly census data is derived from the underlying Statistics New Zealand classifications and geographic building blocks used to create the GCH. A co-design process involving those with an understanding of Aotearoa New Zealand's rural population and health services determined appropriate criteria and cut-off points for the GCH categories. Reasoning for the criteria, cut-off points and any special cases are outlined. In line with the UA the input variables are limited to population size, density, and travel time.
	4) Use appropriate algorithms, criteria, and cut-off points	
	5) Be based on simplicity including parsimonious indicators	
	6) Derived from high quality data	
	7) Be based on a replicable process	
	8) Stable over time but ability to adjust for changes	
Spatial unit	Be based on a spatial unit that: 9) Is consistent with data availability	Statistical Area 1s (SA1s) are the smallest geographic unit for the reporting of Statistics New Zealand population data, and the building blocks of the UA. SA1s are designed for examination of spatial variation while maintaining confidentiality and anonymity. The GCH classifies every SA1 in NZ as rural or urban, and broader regions of interest can be developed from SA1s.
	10) Enables confidential examination of small area differences	
	11) Ensures comprehensive coverage and aggregation into broader regions	
Validity	12) Have categories that maximise internal homogeneity and external heterogeneity	The internal homogeneity and external heterogeneity of categories with respect to health were quantitatively validated using Primary Health Organisation enrolment data. Extensive consultation with key stakeholders has ensured that the GCH reflects "common-sense" understandings of what is and is not rural.
	13) Have on-the-ground validity and align closely with a heuristic sense of what is and is not rural	

Appendix 2: Border issues and additional considerations.

Modifications and special cases outside of the changes to the population and drive time thresholds outlined above have been avoided as much as possible. However, one important challenge has been that, inside a health discourse, the most meaningful population threshold likely sits within the medium urban area category. Places at the upper end of the population threshold (close to 30,000 residents) tend to be more urban in nature than towns at the smaller end of the scale (closer to 10,000 residents). To maintain consistency with the SSGA18 and UA, we have avoided splitting the medium urban areas category. However, we have identified four places—Timaru, Blenheim, Whakatāne, and Masterton—which are classed in the UR2018 as medium urban areas but have larger populations than other medium urban areas. Furthermore, these centers, for historic reasons, also have substantially different health services to most other medium urban areas, setting these places apart as special cases. On this basis Timaru, Blenheim, Whakatāne, and Masterton are more appropriately included in the U2 category in the GCH. Furthermore, despite being classified as a small urban area in the UR2018, Greymouth has many of the characteristics of a medium urban area and is treated like a medium urban area in the UA. Therefore, we have also classed Greymouth as a medium urban area in the GCH. Finally, the rural settlement of Te Poi in the Matamata-Piako region was originally classed as U2 due to its travel time to the edge of Tauranga. However, we received strong feedback during the consultation process that this was incorrect. The Kaimai ranges present a significant geographic barrier, and commuter data from the Statistics New Zealand (2021) Functional Urban Areas classification indicates that the Te Poi area is not a functional part of Tauranga City. Consistent feedback that we received from NRHAG and stakeholders was that all of these additional considerations and modifications were appropriate changes and produced a better reflection of the "on-the-ground" reality.

Appendix 3: Overlap between the population defined as urban and rural according to the GCH, UA, and UREP.

GCH classification		Total		Overlap between GCH and UA classifications			Overlap between GCH and UREP classifications		
		n	%	Rural	Urban	% Agreement	Rural	Urban	% Agreement
Urban		3,806,307	81%						
	U1	2,961,138	63%	288,714	2,672,424	90%	139,557	2,821,581	95%
	U2	845,169	18%	197,223	647,946	77%	102,852	742,317	88%
Rural		892,881	19%						
	R1	570,147	12%	420,009	150,138	74%	251,382	318,765	44%
	R2	266,928	6%	266,928	0	100%	138,504	128,424	52%
	R3	55,806	1%	55,806	0	100%	52,914	2,892	95%
Total		4,699,188		1,228,680	3,470,508		685,209	4,013,979	

Motivators and barriers to general surgery as a career among junior doctors and medical students in New Zealand

Leah Boyle, Adam Payne, Sharon Jay, Jeremy Rossaak

ABSTRACT

AIM: Increasing diversity among surgeons is a priority of the Royal Australasian College of Surgeons (RACS).[1] This study aimed to identify motivators and barriers to general surgery among junior doctors (JD) and medical students (MS) to help guide the recruitment of under-represented minorities into surgical training.

METHODS: An online survey was sent to 2,170 participants—1,327 JD in New Zealand and 843 MS at The University of Auckland (UA). Participants were asked about motivators or barriers to a career in general surgery.

RESULTS: Twenty-one percent (452/2170) completed the survey. Most were female (65.1%), NZ European (53.6%) and MS (62.4%). Factors guiding career decision include interest in clinical and practical aspects (weighted average 4.43 and 4.34, respectively) and work–life balance (weighted average 4.11). Barriers to training were long hours and feeling overwhelmed (weighted average 4.05 and 3.64, respectively). There were perceived biases with 79.7% reporting a gender bias and 99.7% reporting male over-representation. Similarly, 68.4% reported an ethnicity bias; 97% reporting NZ European over-representation. 92.2% considered mentorship important but only 15.3% have a mentor.

CONCLUSION: This study identified motivators and barriers to general surgery and perceived gender and ethnicity biases. With demand for a diverse surgical workforce, there should be focus on recruitment of underrepresented minorities and mentorship.

Increasing surgical diversity among trainees is a priority of the Royal Australasian College of Surgeons (RACS).[1] This fits in with the Building Respect, Improving Patient Safety Action Plan on discrimination, bullying and sexual harassment in surgery, launched in 2015, which supported actively working with medical schools to encourage surgery as a career.[2]

However, it is clear that career direction in medicine is a multi-factorial process that involves internal and external factors. Personal or internal factors include academic interest in a field, competencies and lifestyle factors.[3,4] External factors include the influence of previous experience on rotations.[5] For surgical specialties, systematic review suggests experience in the operating theatre as a student is the single most important factor to promote interest in surgery.[6] Despite this, less than 10% of students in a recent New Zealand survey felt their medical school exposure was sufficient for making an informed career choice, raising concern regarding exposure to surgery for junior doctors (JD) and medical students (MS).[7]

A positive role model has been shown to guide career choice in general surgery.[5] The development of mentorship relationships is important for MS and JD to provide support and guide career decision making.[5,8,9] Unfortunately, few students in New Zealand feel they have adequate mentorship, with only 10% in a recent survey of UA students reporting having a mentor.[7]

Possible deterrents for a career in General Surgery include poor work–life balance and negative experience on rotations at medical school.[5] There are also wider societal and cultural factors influencing a career in general surgery. There is a longstanding over-representation of males and the NZ European ethnicity in medicine in general.[1,10,11]

The aim of this study was to identify motivators and conversely the barriers to a career in general Surgery among JD and MS in New Zealand. Understanding these factors may improve recruitment and training opportunities in general surgery and importantly facilitate diversity in general surgical trainees.

Methods

An online survey (Appendix 1) was sent to 2,170 participants (1,327 JD and 843 MS). JD included all doctors employed in a house officer role nationwide. These are predominantly postgraduate years one and two. MS were clinical students at The University of Auckland School of Medicine in years four to six.

The researchers sent an email of invitation (Appendix 2) to the student convener at the University of Auckland (UA) and to the resident medical officer (RMO) coordinators at each of the twenty district health boards (DHBs) in New Zealand. This initial email asked to forward a separate email of invitation (Appendix 3) to MS and JD respectively, as well as reminder emails (Appendix 4). The invitation email sent to participants explained the aim of the study and outlined the consent process. This method facilitated anonymity as the researchers did not have access to the participants emails. The survey remained open for three weeks, with reminder emails to participate sent after one and two weeks.

In the initial email, the student convener and RMO coordinator were asked to reply to the researchers to confirm receival and participation. Confirmation from the medical school student convenor was immediate. Only three DHBs responded immediately. When the RMO coordinator had not responded to the researchers within the first week, they were telephoned to clarify whether they had received the initial email, and then forwarded it on to participants. The researchers phoned each RMO coordinator a maximum of three times until a response was achieved. This ensured that all twenty DHBs had forwarded the email to participants.

The survey consisted of closed "yes" and "no" questions, multi-choice or Likert response questions on demographic data (age, gender, ethnicity, level of training and about family make-up) and motivators or barriers to general surgery. They were also asked about whether they perceived an ethnicity or gender bias which could include their own self-selection bias, or a perceived bias from selection committees. Respondents were able skip questions and still complete the survey.

Results remained anonymous and were analysed using Excel. Weighted averages were used for questions with Likert scales (1—not at all important; 2—not so important; 3—somewhat important; 4—very important; 5—extremely important). For the key motivators (question 8) and barriers (question 9) analysis was by subgroups of gender and ethnicity (Appendix 1). If participants identified with more than one ethnicity, their response was included in all of the ethnicities they identified with.

Ethical approval was obtained via The University of Auckland Human Participants Ethics Committee (UAHPEC21921).

Results

Demographics

The response rate was 21 % with a total of 452/2170 responses. The demographics of participants are summarised in Table 1. In terms of family, the majority (95.6%, n=431/451) had no children and over half (51.4%, n=232/451) were in a long-term relationship. Twenty-one point five percent (n =97/451) of respondents were very likely or likely to pursue a career in general surgery (Figure 1).

Motivators influencing a career in general surgery

Over half of the respondents (66.2%, n=298/450) see their medical student experience as very or extremely important in determining their career choice. In terms of experience to date, almost all respondents (94.3%, n=399/423) have had the opportunity to assist in theatre, and 13.0% (n=55/423) have performed an operation as the primary surgeon. Over half of respondents have had the opportunity to see and assess patients independently, with 59.1% (n=253/423) having experience admitting acute patients and 51.5% (n=218/423) seeing patients in clinic. Twenty-six percent (n=108/423) have had experience with research.

The most important factors guiding career choice were interest in clinical aspects (weighted average 4.43), interest in practical aspects (weighted average 4.34) and work life balance (weighted average 4.11) (Table 2). The least important aspect for career choice was research opportunities (weighted average 2.64). Factors guiding career choice are analysed by gender and ethnicity in Table 2. Of note, females place more importance on family commitments guiding their career choice compared to males (3.86 vs 3.66) whilst males place more importance on income (3.25 vs 2.91).

Regarding ethnicity when compared to all respondents, Māori place greater importance on a mentor or role model (4.05 vs. 3.87) and experience on prior rotations (4.17 vs 3.96). Importantly, Pasifika peoples place the greatest importance on family commitments when compared to all respondents (4.30 vs 3.78) (Table 2). Almost all respondents (92.2%, n=416/451) consider having a mentor important; 34.6% somewhat important, 39.3% very important and 18.4% extremely important. Despite this, only 15.3% (n=69/451) reported currently have a mentor.

Table 1: Demographics of respondents.

Demographic	n (%)
Age (y)	
21–23	178 (39.5)
24–26	174 (38.6)
27–29	54 (12.0)
30–32	22 (4.9)
33+	23 (5.1)
Gender	
Female	293 (65.1)
Male	153 (34)
Transgender	-
Gender diverse	1 (0.2)
Non-binary	1 (0.2)
Prefer not to say	2 (0.4)
Ethnicity	
NZ European	230 (53.6)
Chinese	73 (16.2)
Māori	54 (12.6)
Pasifika	20 (4.4)
Indian	27 (6.3)
Japanese	2 (0.5)
Other	118 (27.5)
Training level	
4th year MS	79 (17.5)
5th year MS	102 (22.6)
Trainee Intern (6th year MS)	96 (21.3)
PGY1 House Officer	62 (13.8)
PGY2 House Officer	88 (19.5)
PGY3+ House Officer	24 (5.3)

Figure 1: Likelihood of a career in general surgery.

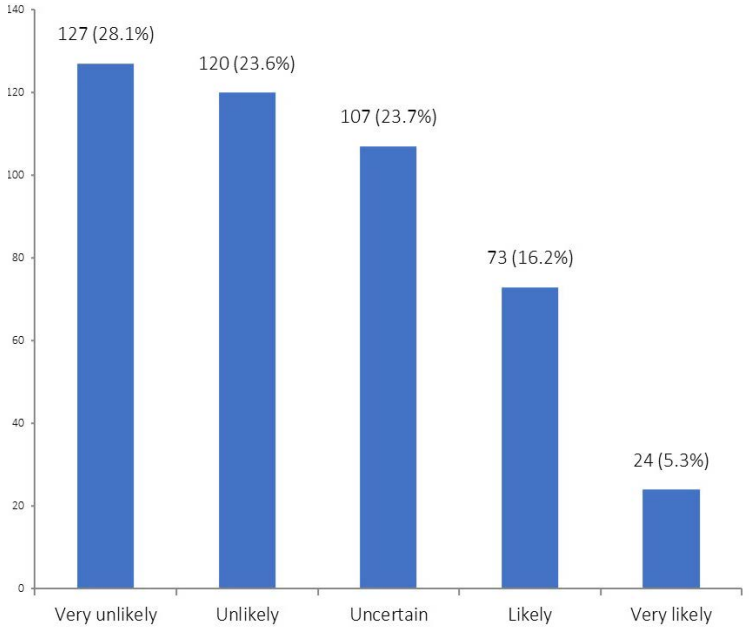

Table 2: Motivators guiding career decision by gender and ethnicity.

Weighted average	Clinical practice	Practical aspect	Mentor or role model	Research	Income	Work–life balance	Interest in pathology	Experience on rotation	Family
All (452)	**4.39**	**4.29**	**3.83**	**2.69**	**3.00**	**4.06**	**3.17**	**3.96**	**3.78**
Gender									
Female (293)	4.43	4.34	3.86	2.64	2.91	4.12	3.15	4.01	3.86
Male (153)	4.29	4.20	3.78	2.76	3.25	3.98	3.18	3.88	3.66
Other (4)	4.80	4.20	4.00	2.60	1.40	4.00	3.60	3.80	3.40
Ethnicity									
NZ European (230)	5.00	4.27	3.77	2.56	2.86	4.11	3.17	3.92	3.80
Chinese (73)	4.43	4.40	3.84	2.67	3.15	3.90	3.26	3.97	3.68
Māori (54)	4.44	4.47	4.05	2.81	2.98	4.07	3.21	4.17	3.89
Indian (27)	4.54	4.27	3.81	3.38	3.19	3.96	3.35	3.85	3.73
Pasifika (20)	4.26	4.09	3.91	3.13	2.91	4.56	3.48	4.22	4.30
Japanese (2)	4.50	3.50	4.50	2.50	4.00	4.50	4.00	4.50	4.50
Other (118)	4.30	4.25	4.04	2.73	3.22	4.16	3.15	4.14	4.00

Table 3: Barriers to general surgery by gender and ethnicity.

Weighted average	Boy's Club	Hours	Physical demands	Feeling over-whelmed	Not good enough	Fear of not fitting in
All (452)	**3.05**	**4.05**	**3.11**	**3.64**	**3.49**	**3.07**
Gender						
Female (293)	3.35	4.11	3.27	3.73	3.63	3.23
Male (153)	2.46	3.91	2.83	3.49	3.24	2.79
Other (4)	3.40	4.00	3.00	3.40	2.20	2.40
Ethnicity						
NZ European (230)	3.22	4.10	2.94	3.62	3.41	3.02
Chinese (73)	2.95	3.89	3.83	3.72	3.59	3.19
Māori (54)	3.28	3.93	2.92	3.68	3.59	3.11
Indian (27)	2.92	3.88	3.34	3.73	3.92	3.23
Pasifika (20)	2.78	4.57	3.48	3.96	3.70	3.00
Japanese (2)	3.00	5.00	4.00	3.00	4.00	3.50
Other (118)	2.91	4.13	3.33	3.69	3.55	3.30

Barriers influencing a career in general surgery

There were perceived gender and ethnicity biases in general surgery among respondents. Seventy-nine point seven percent (n=357/448) reported a gender bias, with 99.7% (n=356/357) of these reporting that males are over-represented. Similarly, 68.4% (n=307/449) reported an ethnicity bias. Ninety-seven percent of these (298/307) reported NZ Europeans as being over-represented.

The most significant barrier for choosing general surgery as a career amongst all respondents was perceived hours of work (4.05) and when broken down by gender, hours was a more significant barrier for females (4.11 vs 3.91) (Table 3).

Discussion

This study demonstrated key factors, both motivators and barriers influencing career decision for MS and JD with a particular focus on general surgery. Key motivators guiding career choice were interest in clinical aspects, practical aspects, and work–life balance. In terms of barriers, the most important was perceived hours of work. Of note, all six barriers were more significant for females.

This study also demonstrated there is an unmet need for mentorship, with 92% considering mentorship important but only 15% currently having a mentor. A perceived over-representation of males—79.7% (n=357/448); and Pākehā/NZ Europeans—68.4% (n=307/449) were also found.

These results are in alignment with a previous meta-analysis indicating academic interests and lifestyle factors were the most important factors guiding career choice.[3] It is also known that experience as a medical student is important to guide career choice.[3–6] This is supported by our findings, with over two thirds of participants seeing their medical school experience as guiding their career choice. Thirteen percent of our participants had performed an operation under supervision as the primary surgeon. As such tailoring medical school and house officer training requirements to ensure adequate surgical exposure may help to attract candidates to general surgery.[6]

In terms of barriers to surgical training, our data supports previous studies with perceived hours of work being a big determinant of choice.[3] Surgical careers will need to find innovative ways of managing hours at work. Other important barriers were feeling overwhelmed and not feeling good enough. The unmet need for mentorship in

this study is similar to prior research also among New Zealand MS.[7] This was especially important to Māori respondents. Improving mentorship may help address some of the aforementioned barriers, as effective mentorship is known to support junior staff both psychologically and in career decision-making.[4,10]

In this study, all six barriers were more significant for females than males. This is similar to a recent qualitative study evaluating view of minorities in surgical training, where women report being discouraged from a surgical career, in particular due to family commitments.[11] Likewise, in this study females also placed more importance on family commitments than males. There was a reported under-representation of females in surgical specialties in this study with which is not a new finding.[12,13] Female surgeons make up 25% of the general surgical workforce in New Zealand, and only 13% of senior surgical positions across Australasia.[13,15]

Similarly, this study has identified a perceived ethnicity bias in general surgery, with 97% of those who reported a bias, reporting over-representation of NZ Europeans/Pākehā. It is well known that NZ Europeans/Pākehā are over-represented in medicine, particularly in surgery.[12] There is no publicly available ethnicity data of general surgeons in New Zealand. Similar to recent interviews with minorities in surgical training, these findings in our study suggest the need to improve diversity in surgical training in New Zealand, aligning with the RACS Diversity Inclusion Plan which one of its goals being "to embrace diversity and foster gender equity'"[1,14]

This study is the first of its kind in New Zealand, and has a large sample size involving JD nationwide and MS at the UA. As such it provides unique information to help guide training opportunities in general surgery. The results of this study should be interpreted with respect to its limitations. The response rate was 21%, and it's possible that MS and JD who had already decided on a surgical career were less likely to participate. To facilitate anonymity, the specific hospital that respondents were working in was not known by the investigators and as such it cannot be established whether exposure and experience in general surgery is different in tertiary hospitals compared to smaller rural hospitals. Knowledge of this difference may enable specific tailoring of mentorship and training opportunities in different regions. Given the role of a JD is reasonably standardised across New Zealand, application of these results outside of New Zealand is unclear. This study did not evaluate the views of training or pre-vocational training registrars. Knowledge of barriers and challenges trainees face is also essential to guide future training programmes. Perhaps and more importantly, a study would benefit from capturing the view of registrars who have initially expressed interest in a surgical career, but then opted for an alternative career. Future work could use a similar survey to evaluate the opinions of these groups.

This study has identified key motivators and barriers towards general surgery among MS and JD. It has also shown there is a perceived over-representation of males and NZ Europeans/Pākehā and an unmet need for mentorship. An acknowledgement of factors influencing a career choice in general surgery could help to improve opportunities in general surgery to diversify our workforce.

COMPETING INTERESTS
Nil.

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Appendices

Appendix 1: Survey.

View towards general surgery as a specialty

1. What is your age?

   a) 21–23 years
   b) 24–26 years
   c) 27–29 years
   d) 30–32 years
   e) 33 years+

2. What gender do you identify with?

   a) Female
   b) Male
   c) Transgender
   d) Gender diverse
   e) Non-binary
   f) Prefer not to say

3. What ethnic group do you identify with?

   a) NZ European/Pākehā
   b) Māori
   c) Samoan
   d) Cook island Māori
   e) Tongan
   f) Niuean
   g) Chinese
   h) Japanese
   i) Indian
   j) Other

4. Do you have a partner?

   a) Yes (married or long-term)
   b) No

5. Do you have children?

   a) Yes – 1 child
   b) Yes – 2 children
   c) Yes – 3 children
   d) Yes – 4+ children
   e) No

6. What is your current level of medial training?

   a) 4th year medical student
   b) 5th year medical student
   c) Trainee intern
   d) PGY1 House Officer
   e) PGY2 House Officer
   f) PGY3+

7. How likely are you to pursue a career in general surgery?

   a) Very unlikely
   b) Unlikely
   c) Uncertain
   d) Likely
   e) Very likely

8. Please rate the following factors in terms of how you have or how you might choose your career. (Not at all important, not so important, somewhat important, very important, extremely important.)

   a) Interest in clinical practice related to your field
   b) Interest in practical aspect related to your field
   c) Senior mentor or role model
   d) Research opportunities
   e) Income
   f) Work–life balance
   g) Interest in pathology related to your field
   h) Experience on a rotation related to your field
   i) Family commitments

9. How relevant do you see the following as barriers to general surgery as a career? (Not at all important, not so important, somewhat important, very important, extremely important.)

   a) Boy's Club
   b) Hours
   c) Physical demands
   d) Regularly feeling overwhelmed
   e) Not feeling good enough
   f) Fear of not fitting in

10. How important is/was your experiences as a medical student in determining your career choice?

    a) Not at all important
    b) Not so important
    c) Somewhat important
    d) Very important
    e) Extremely important

11. In your training so far, which have you had the opportunity to do?

    a) Admit surgical patients independently
    b) Assist in theatre
    c) Perform an operation as primary surgeon
    d) Undertake research
    e) See patients independently in clinic

12. Do you believe there is a gender bias in general surgery?

a) Yes
b) No

13. If answered yes, which gender is over-represented?

a) Female
b) Male
c) N/A – answered 'no' to the previous question

14. Do you believe there is an ethnicity bias in general surgery?

a) Yes
b) No

15. If answered yes, which ethnicity is over-represented?

a) NZ European/Pākehā
b) Māori
c) Samoan
d) Cook island Māori
e) Tongan
f) Niuean
g) Chinese
h) Japanese
i) Indian
j) Other
k) N/A – I answered no to the previous question

16. Do you currently have a mentor?

a) Yes
b) No

17. How important do you consider having a mentor as part of your career planning?

a) Not at all important
b) Not so important
c) Somewhat important
d) Very important
e) Extremely important

Appendix 2: Email sent to student convenor and RMO coordinators.

Dear RMO coordinator or student convenor,

We are conducting a survey on 'Views towards a career in General Surgery'. We are hoping to identify motivators and barriers contributing to career choice, in particular general surgery among junior doctors and medical students. This will be used to improve future training opportunities in both surgical and non-surgical specialties.

We are sending this survey to all postgraduate year one- and two-house officers in New Zealand and all 4th, 5th and 6th year medical students at the University of Auckland.

We ask if you could kindly forward the following e-mail to all post graduate year one and two doctors at your DHB followed by a reminder e-mail one and two weeks following this.

Many thanks for your input with this

Dr Leah Boyle

Email 1: Initial invitation.

Dear Junior Doctor (or Medical Student),

We invite you to participate in our survey 'Views towards a career in General Surgery'. We are hoping to identify motivators and barriers contributing to career choice, in particular general surgery among junior doctors and medical students. This will be used to improve future training opportunities in both surgical and non-surgical specialties. This survey has been sent to all postgraduate year one- and two-house officers in New Zealand and all 4th, 5th and 6th year medical students at The University of Auckland.

Please be aware that your participation or non-participation in the study will not affect your grades, relationship with the university, run assessment or training opportunities. No identifying information is required to complete the survey therefore data will be anonymous. Therefore, once you have completed the survey you will not be able to withdraw your data. Data will be stored on a secure device for six years and then destroyed. We plan to publish this information in a peer-reviewed journal.

This survey has been approved by The University of Auckland Human Participants Ethics Committee on … for three years. Reference number … Participation is voluntary and your consent to participate in the study is implied by taking part.

Further information about this survey be obtained from contacting Dr Leah Boyle (leah.boyle@bopdhb.govt.nz) or Mr Jeremy Rossaak (jeremy.rossaak@bopdhb.govt.nz). For any queries regarding ethical concerns, you may contact the Chair, The University of Auckland Human Participants Ethics Committee on 09 373-7599 ext. 83711 or email: humanethics@auckland.ac.nz. (9)

We appreciate your time and input.

Please click the following link to participate: _____

Email 2: Reminder email (to be sent one and two weeks following initial invitation date).

Dear Junior Doctor (or Medical Student)

This is a reminder to participate in our survey 'Views towards a career in General Surgery'.

We appreciate your time and input.

Please click the following link to participate: _____

Appendix 3: Invitation to participate sent to medical students and junior doctors.

Dear Junior Doctor/Medical student,

We invite you to participate in our survey 'Views towards a career in General Surgery '. We are hoping to identify motivators and barriers contributing to career choice, in particular general surgery among junior doctors and medical students. This will be used to improve future training opportunities in both surgical and non-surgical specialties. This survey has been sent to all postgraduate year one- and two-house officers in New Zealand and all 4th, 5th and 6th year medical students at The University of Auckland.

Please be aware that your participation or non-participation in the study will not affect your grades, relationship with the university, run assessment or training opportunities. No identifying information is required to complete the survey therefore data will be anonymous. Therefore, once you have completed the survey you will not be able to withdraw your data. Data will be stored on a secure device for six years and then destroyed. We plan to publish this information in a peer reviewed journal.

This survey has been approved by The University of Auckland Human Participants Ethics Committee on 23/2/21 for three years, reference number UAHPEC 21921. Participation is voluntary and your consent to participate in the study is implied by taking part.

Further information about this survey be obtained from contacting Dr Leah Boyle (leah.boyle@bopdhb.govt.nz) or Mr Jeremy Rossaak (jeremy.rossaak@bopdhb.govt.nz). For any queries regarding ethical concerns, you may contact the Chair, The University of Auckland Human Participants Ethics Committee on 09 373-7599 ext. 83711 or email: humanethics@auckland.ac.nz.

We appreciate your time and input.

Please click the following link to participate: _____

Appendix 4: Reminder email sent to medical students and junior doctors.

Dear Junior Doctor/Medical Student,

This is a reminder to participate in our survey 'Views towards a career in General Surgery'.

We appreciate your time and input.

Please click the following link to participate: _____

A comparison of the performance of saliva and nasopharyngeal nucleic acid amplification testing for the detection of SARS-CoV-2 in New Zealand

Gary McAuliffe, Timothy Blackmore, Juliet Elvy, Shivani Fox-Lewis, Brent Gilpin, Jenny Grant, Radhika Nagappan, Erasmus Smit, Chor Ee Tan, Fernalynn Tiongko, James Ussher

ABSTRACT

AIM: To compare detection of SARS-CoV-2 from paired nasopharyngeal swabs (NPS) and saliva using molecular methods in common use for testing swabs in New Zealand.

METHOD: Samples from individuals testing positive for SARS-CoV-2 in Auckland, Wellington and Dunedin were tested at the local laboratories using methods previously established for these sample types.

RESULTS: One hundred and ninety-six paired samples from unique individuals were tested, with 46 (23%) positive from either sample type, of which 43/46 (93%) tested positive from NPS, and 42/46 (91%) from saliva, indicating no significant difference in performance between sample types (p=0.69). The average Δ Ct between saliva and nasopharyngeal swabs overall across the sample set was 0.22 cycles, indicating excellent concordance; however, the difference between NPS and saliva collected from the same individual was quite variable with up to 19 cycles difference between the sample types.

CONCLUSION: We found that saliva is an equivalent sample type to nasopharyngeal swab for the detection of SARS-CoV-2 in our laboratories using multiple assay combinations and is suitable for use as a diagnostic and surveillance test for selected groups of individuals.

Worldwide, molecular detection of SARS-CoV-2 is primarily focussed on swab-based sampling of the nasopharyngeal, nasal, and/or oropharyngeal cavities, but as the pandemic has progressed there has been increasing interest in the role of saliva as a sample type.[1]

Saliva holds several advantages over swab based techniques: it can be self-collected, which may reduce pressure on healthcare providers in the community, and it is less invasive, which may be desirable for people who require frequent testing.[2] Early on in the pandemic, where swabs and extraction reagents were scarce, an ability to bypass these requirements was also an advantage though this has largely been overcome by increased manufacturing capability and wider use of integrated machines combining extraction and amplification.[3]

Several systematic reviews have now been published, comparing molecular detection of SARS-CoV-2 from saliva and swab-based techniques, and these have shown that the sensitivity is similar,[1,4,5] though the studies are heterogenous in nature and several have indicated poorer performance and technical issues depending on methodology and use scenario.[6,7]

However, only a limited number of diagnostic companies have sought authorisation for their swab based molecular tests for testing saliva,[8] which prompts the question as to whether commonly used swab based nucleic acid amplification tests (NAATs) can be repurposed for saliva.

We, therefore, sought to compare detection of SARS-CoV-2 from paired nasopharyngeal swabs and saliva in order to understand the performance of saliva using NAATs in common use for testing swabs in New Zealand.

Methods

LabPLUS, Auckland Hospital

One hundred and seventy-three paired saliva and nasopharyngeal samples were available from 150 individuals at a managed isolation facility (MIF) for international arrivals in 2020 and 23 patients hospitalised with COVID-19 during the community outbreak in Auckland in August and September 2021.

Nucleic acids were extracted from 200µL of saliva or 200µL of viral transport medium (VTM) containing the nasopharyngeal swab on the MagNA Pure 96 with the MagNA Pure 96 DNA and

Viral NA Small Volume extraction kit (Roche Diagnostic, Germany), prior to testing on the LightCycler 480 instrument (Roche), using the in-house E gene assay according to previously described method.[9]

For the hospitalised patient samples, 200µL of saliva or VTM (nasopharyngeal swab) were extracted on the KingFisher™ Flex using NucleoMag (Machery-Nagel) extraction kits prior to testing on the ABI 7500 (Thermofisher, US) instrument using the TaqPath COVID-19 Combi kit (Thermofisher).

Southern Community Laboratories, Dunedin

Thirteen paired saliva and nasopharyngeal samples were available from crew on board a quarantined ship. 400µL of saliva or VTM (nasopharyngeal swab) were extracted on the KingFisher™ Flex using the MagMAX™ Viral/Pathogen II Nucleic Acid Isolation Kit prior to testing with the TaqPath™ COVID-19 Combo assay on QuantStudio™ 7500 Real Time PCR instrument.

Southern Community Laboratories, Wellington

Paired saliva and nasopharyngeal samples from two maritime crew members and eight persons in the Wellington managed isolation and quarantine facility (MIQ) were included in this study. 200µL of each sample was extracted on the MagNA Pure 96 using the MagNA Pure 96 DNA and Viral NA Small Volume Kit (Roche). RT-PCR for SARS-CoV-2 was performed on the maritime samples using the LightMix SARS-CoV-2 (E-gene) assay (Roche), and on the MIQ samples using the Perkin Elmer SARS-CoV-2 QRT-PCR assay according to the manufacturer's instructions.

Comparisons

Analysis of the data set was performed retrospectively on samples which had been gathered independently and tested at the study sites across New Zealand as part of validation studies. To be eligible for inclusion, both sample types were required to have been collected from an individual on the same day.

Delta (Δ) Ct (the difference between cycle threshold values) was calculated for nasopharyngeal swabs and saliva based on a single gene. Chi-squared tests were used to compare proportions. Fisher Exact tests were used to compare performance by laboratory and assay.

Ethics

The MIF samples tested at Auckland Hospital were taken as part of an Institute of Environmental Science and Research (ESR) excretion of SARS-CoV-2 in saliva and faeces study for which ethical approval for the study was obtained from the Health and Disability Ethics Committee (ethics reference: 20/NTB/216/AM01). Individuals at Auckland Hospital, and the other sites provided, informed verbal consent to partake in assay validation by providing additional samples; this approach was endorsed by the New Zealand Ministry of Health.

Results

One hundred and ninety-six paired nasopharyngeal and saliva samples from unique individuals were tested, with 46 (23%) positive from either sample type, 43 (93% of total positive) from nasopharyngeal swab, and 42 (91% of total positive) from saliva, indicating no significant difference between performance of the two sample types (p=0.69). In three instances, saliva samples were positive where nasopharyngeal swabs were negative, and in four instances the nasopharyngeal swabs were positive and the saliva samples were negative. Comparing the assays, there was no statistically significant difference between the performance of samples at any laboratory or assay combination (p=0.069); see Table 1 for performance at specific laboratory and assay combinations.

The positive percentage agreement of saliva compared with nasopharyngeal swab was 91%, (95%CI 81.2–95.5%) and negative percentage agreement was 98%, (95%CI 95.4–99.4%), with a kappa of 0.90 (95%CI 0.77–0.96%).

In comparison the percentage agreement of nasopharyngeal swabs compared with saliva was 92.9% (95%CI 83.2–97.7%) and negative percentage agreement was 97.4% (95%CI 94.8–98.7%) with a kappa of 0.90% (0.77–0.96%).

The average difference in Ct between saliva and nasopharyngeal swabs across the sample set was 0.22 cycles, indicating excellent concordance; however, the difference between nasopharyngeal swabs and saliva collected from the same individual was quite variable with up to 19 cycles difference between the sample types (see Table 1); 20/46 (43%) of positive saliva samples had lower Cts (implying higher viral loads) compared with the nasopharyngeal swab, and 26/46 (57%) had lower Cts in the nasopharyngeal swab (p=0.21).

Table 1: Results of the NPS vs saliva as sample type for SARS CoV-2 testing processed across several laboratories in New Zealand.

Laboratory	Extraction kit/platform	SARS-CoV-2 assay/ platform	No. of samples tested	NPS or saliva (% positive)	NPS (% positive)	Saliva (%positive)	Δ Ct range
LabPLUS Auckland	Nucleomag†/ Kingfisher	Taqpath/ ABI 7500	23	23 (100)	22 (96)	22 (96)	-16.67–15.24
	MP96††	In-house E/ LightCycler	150	7 (5)	7 (100)	5 (71)	-8.63–19.07
SCL, Dunedin	MagMax‡/ Kingfisher	Taqpath/ Quantstudio	13	11 (85)	10 (91)	11 (91)	-11.4–9.8
	MP96††	Light Mix E/ LightCycler 480	2	2 (100)	1 (50)	2 (100)	-7.83–0.93
SCL, Wellington	MP96††	PerkinElmer/ LightCycler 480	8	3 (38)	3 (100)	2 (67)	1.2–12.53
Total			196	46 (23)	43 (93)	42 (91)	-16.67–19.07

Nucleomag†: Pathogen viral RNA/DNA isolation kit, MagMax ‡: Viral/Pathogen II Nucleic Acid Isolation Kit, MP96††: DNA and Viral Nucleic Acid Small Volume extraction kit, SCL: Southern Community Laboratories, NPS: Nasopharyngeal swab.

Discussion

We compared the performance of nasopharyngeal swabs with saliva as sample types for the molecular detection of SARS-CoV-2 at three laboratories, across five test combinations and found that the sensitivity was similar between both sample types. It is notable that a non-statistically significant lower overall detection rate was seen for saliva compared with NPS in our dataset (91% versus 93%). Both of these observations are consistent with findings of several meta-analyses.[1,4,5] Overall, these findings support that saliva is an appropriate sample type for detection of SARS-CoV-2 by NAAT for diagnosis and surveillance in New Zealand.

We found that saliva and nasopharyngeal swabs detected positives where the other tested negative, and vice versa, and that the cycle threshold, an imperfect marker of viral load for semi-quantitative assays, was quite variable between the two sample types. These findings were not significantly skewed towards one sample type: there was a wide range of difference between cycles thresholds of between -16.67 to 19.07 cycles between saliva and NPS across the dataset, and whilst there was a predominance of higher viral loads in NPS for 57% of positives, the viral load was higher in saliva in the other 43%, with an net overall difference of only 0.22 cycles between sample types. This variability in viral load is most likely explained by differential viral dynamics in the anatomical spaces which change over time,[10] is a limitation of either sample type and indicates neither sample type was significantly less sensitive than the other.

Shedding of viral RNA via the nasopharynx can occur for some time following infection, with a median shedding time of 19 days reported in a large population-based cohort in Canada,[11] and as the prevalence of past infections rises, detection of non-viable RNA can potentially lead to unnecessary isolation of individuals. There is some evidence that saliva shedding is highest in the first week of illness and drops thereafter, indicating it may better reflect infectiousness compared with a nasopharyngeal PCR,[12] which may be of benefit in the pivot from an elimination strategy to living with endemic COVID-19.

Over the New Zealand Delta outbreak, saliva had a role in the public health response in New Zealand, particularly as an option for regular surveillance testing of international border workers or essential workers crossing regional boundaries,[13,14] and in some settings for healthcare workers caring for COVID-19 infected patients. It is not quite clear what role saliva NAAT testing will have

in the New Zealand public health response in the future. During the New Zealand Omicron outbreak, general surveillance testing has reduced and rapid antigen testing (RAT) has largely replaced saliva NAAT testing, and has greatly reduced the volume of laboratory NAATs. RAT has similar advantages to saliva NAAT for frequent asymptomatic testing,[15,16] with additional advantages such as decentralisation of testing, self-testing, lower cost, and ability to provide results in as little as 10 minutes.[17] Judicious use of this modality can reduce reliance on laboratories and save resources for diagnostic testing for public health and healthcare purposes.

Saliva appears attractive as one of the possible alternative sample types for individuals where swab-based testing is not tolerated. Given that New Zealand is now several months divorced from its elimination approach, it is now less critical to identify every case of COVID-19 in the community, and providing more tolerable options to nasopharyngeal swabs is desirable for people presenting for testing. In addition to saliva, swabbing of the throat, mid-turbinates or anterior nares alone and self-swabbing could all be offered as alternative sample types where logistical and operational considerations allow.

Saliva NAAT testing is not universally available in New Zealand laboratories, due to largely practical reasons: saliva is a heterogeneous matrix and in common with others,[4] we have found that it requires different pre-processing steps compared with swab-based testing to support high-throughput workflows. These steps may reduce the efficiency of existing workflows (particularly for integrated testing platforms), impacting on turnaround times for those individuals tested. Secondly, because diagnostic companies have not sought authorisation for their products to be used for saliva, the requirement for additional validation of the sample type is difficult for smaller laboratories to achieve, particularly when under constraints of responding to high NAAT test demand.

The purpose of the study was to compare detection of SARS-CoV-2 from paired nasopharyngeal swabs and saliva in order to understand the performance of saliva using NAATs in common use for testing swabs in New Zealand. There were substantial challenges obtaining this data over the course of the pandemic due to low infection rates in New Zealand, logistical challenges, and inter-agency co-operation. Therefore, this study is imperfect due to its retrospective nature and the small numbers tested at sites outside Auckland, but it nevertheless provides valuable aggregate information on the performance of different sample types for the detection of SARS-CoV-2. Whilst Pitman et al.[18] performed an analysis on imported patient samples from the United States, local data, such as ours, obtained in the New Zealand setting, is essential to help inform national testing strategies. The smaller numbers tested at each location limits our ability to comment on individual assay performance; however, whilst outside the scope of this study, this work has been performed separately and is required before any assay combination is used to test saliva for SARS-CoV-2 by NAAT. It is also important to note there were quite large differences in positivity amongst the participating laboratories, reflecting the different sources of samples. This study was restricted to those samples which were simultaneously paired, in order to best assess analytical and sample factors. This restricted the numbers of samples we were able to include in the study but ensured that the patients' infection status was the same at the time of sampling. Further ongoing studies would be useful to assess the impact of vaccination status, variants, and time from onset of infection on detection in different anatomical spaces.

In summary, we found that saliva is an equivalent sample type to nasopharyngeal swabs for the detection of SARS-CoV-2 in our laboratories using multiple assay combinations and is suitable for use as a diagnostic and surveillance test.

COMPETING INTERESTS:
Nil

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"I teach them. I have no choice": experiences of primary care among transgender people in Aotearoa New Zealand

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ABSTRACT

AIM: This study aims to report primary care experiences among transgender people in Aotearoa New Zealand based on quantitative and qualitative data from a nationwide community-based survey of transgender people.

METHODS: Subsamples with a usual general practitioner were employed from the 2018 *Counting Ourselves* Survey (*n*=871) and the 2018/19 New Zealand Health Survey to assess inequities between these samples in primary care experiences and barriers. Guided by Andersen's Behavioural Model of healthcare access, we conducted a content analysis on comments from *Counting Ourselves* participants (*n*=153) to identify themes about issues of concern for transgender people when accessing primary care.

RESULTS: Transgender participants had greater risk of feeling no confidence in their GPs ($M_{difference}$=0.22; Cohen's d=0.39), reporting barriers accessing primary care due to cost (38.4% vs 17.4%; RR=2.21), and transport issues (13.5% vs 3.0%; RR=4.58) compared to the general population. Content analysis uncovered how transgender people's primary care experiences are shaped by healthcare environments, predisposing characteristics, and enabling resources.

CONCLUSION: Our findings indicate ways to ensure primary care services are inclusive so that all transgender people feel welcome. This requires all primary healthcare professionals to demonstrate core trans-specific cultural safety when providing healthcare to transgender patients.

The term "transgender" commonly refers to people who identify their gender as different from their sex assigned at birth, and can be shortened to trans as an inclusive abbreviation.[1] We use the term transgender to include trans men, trans women, and people with non-binary genders, which includes those who identify as neither a man nor a woman, both a man and a woman, or as moving between genders in a fluid way.[1] In Aotearoa New Zealand, transgender populations also include people who identify with non-Western gender diverse identities such as whakawāhine or tangata ira tāne (Māori), fa'afafine (Samoan), and akava'ine (Cook Islands Māori).[1]

With a growing literature documenting mental health inequities among transgender people,[2,3] researchers are describing the unmet mental health needs of transgender people as a "public health crisis".[4] In recent years, the World Health Organization has updated its International Classification of Diseases, affirming that being transgender is not an illness.[5] From a health equity perspective,[6] the unequal distribution of social determinants—which include access to primary health services and gender-affirming care—are responsible for the heightened level of mental health concerns affecting transgender people. Studies have found higher unmet needs for health services among transgender people when compared to cisgender people,[7] and that transgender people who are unable to access desired health services have a higher likelihood of reporting suicidality.[8]

Andersen's Behavioural Model of healthcare access[9] outlines a framework of enablers and barriers to accessing health services, and it has been applied to theorise the particular barriers and facilitators faced by transgender people.[10] The model suggests that both contextual and individual attributes can influence health service utilisation. These include the health service environment (e.g., providers' knowledge on gender diversity and previous experiences with transgender people), enabling resources that need to be present for people to consider healthcare (e.g., sufficient income, relatively low travel and wait times), and predisposing characteristics that comprise demographic factors (e.g., age and gender) and beliefs about health services.[12]

Most healthcare in Aotearoa New Zealand is provided in the community in general practice primary care facilities, with general practitioners (GPs) being the first point of contact to the health system for most people. GPs' services are free to children aged 13 or under, heavily subsidised for adults with low incomes and operate on public subsidy with variable scales for other adults. As well as providing care for routine health issues for transgender people, GPs sometimes initiate and routinely manage their patients' ongoing gender-affirming hormones needs. GPs also refer transgender people to specialist medical, surgical, and allied gender-affirming healthcare when needed. While secondary care in Aotearoa New Zealand is fully publicly subsidised and available through public hospitals, many forms of gender-affirming care are either not provided at all, are only provided in some regions of the country, or are capped at levels well below demand due to insufficient funding or lack of specialists.[11] In addition, private health insurance in Aotearoa New Zealand explicitly excludes pre-existing gender-affirming healthcare needs, leaving paying privately as the only remaining option. There is work underway in some regions to expand gender-affirming care through primary care, including through GP training.

Existing studies in Aotearoa New Zealand on primary care for transgender people are limited to those who were young adults[2,12] or were accessing health services at one tertiary education setting in Wellington.[13,14] The Youth'19 survey reported a higher rate of foregone healthcare access among transgender high school students compared to their cisgender counterparts (54.7% vs 19.9%).[2] Common themes uncovered from qualitative studies in Aotearoa New Zealand were barriers to accessing care (e.g., cost and lengthy waiting times), a need to resist pathologising narratives when seeking gender-affirming care, and pressure to conform to requirements of readiness assessments in order to obtain access to the healthcare they needed.[12–14]

Transgender people's experiences of accessing primary care have been well-documented in overseas transgender surveys. These include the Australian Trans Pathways study of 463 transgender young people[15] that reported 19.7% were dissatisfied with primary care services and the Canadian Trans PULSE study[16] of 356 transgender adults that found 47.7% of trans men and 54.5% of trans women were not comfortable discussing trans issues with their primary care doctor. The present study expands on previous studies by involving a large sample of transgender people in Aotearoa New Zealand. The objective was to illustrate the primary care experience among transgender people across all age groups. To do this, we conducted analysis of both quantitative and qualitative data on healthcare access and satisfaction from a nationwide community-based survey of transgender people, *Counting Ourselves*. The specific aims were: 1) to investigate differences in primary care experiences between transgender people and a general population sample; and 2) uncover the primary care experiences of transgender people in Aotearoa New Zealand as framed by Andersen's Behavioural Model of healthcare access.[9,10]

Method

Procedure

Counting Ourselves: the Aotearoa New Zealand Trans and Non-Binary Health Survey received ethical approval from the New Zealand Health and Disability Ethics Committee (18/NTB/66/AM01) and was open for participation from June to September 2018 for transgender people living in Aotearoa New Zealand aged 14 or older. Recruitment strategies included social media posts fronted by transgender community leaders, particularly those from harder-to-reach groups including Māori, Pasifika, Asian, older and disabled transgender people, and those living in rural areas. We worked closely with transgender networks, broader rainbow/queer community groups, and health professionals interested in transgender health to promote the survey.

There were 1,178 valid responses to *Counting Ourselves*. Most participants (99%) responded to the online survey through Qualtrics, and the remainder filled out a paper survey. More details about the survey methods can be read in the summary project report.[17]

Participants

A total of 941 participants responded to the general healthcare section of the survey. In this study, we excluded participants who responded "no" (n=63) or "don't know" (n=7) to the question about having a GP clinic or medical centre that they usually visit; this left a final sample of 871 participants. The demographic characteristics of this sample are detailed in Table 1. The largest demographic groups were younger, NZ European/Pākehā, and from urban regions, Auckland and Wellington. There was a high proportion of non-binary participants and similar proportions of trans men and trans women.

Population comparisons

To date, no population-based health surveys in Aotearoa New Zealand have collected data on healthcare accessibility specifically among transgender people. We therefore drew data from the 2018/19 New Zealand Health Survey (NZHS) to identify the differences in experiences of accessing primary care between transgender participants (from *Counting Ourselves*) and the general population (from the NZHS). The 2018/19 NZHS utilised a stratified probability sampling design and applied weighting to yield a sample that is representative of demographic distribution across Aotearoa New Zealand.[19] For the purpose of this analysis, we applied weightings to the 2018/19 NZHS dataset so that the age and ethnicity distribution of the general population matched the *Counting Ourselves* sample. See Appendix 1 for the weightings applied to each age and ethnic group.

Measures

Gender

Participants' gender was requested based on a two-step approach that compared self-defined gender and sex assigned at birth. Trans men included those who selected man, trans man, transsexual, and/or tangata ira tāne as their current gender identity and who were assigned female at birth. Trans women were participants who selected woman, trans woman, transsexual, tangata ira wāhine, and/or whakawāhine as their current gender identity and who were assigned male at birth. Participants who did not meet these criteria but had confirmed before starting the survey that they were "trans or non-binary" were categorised as non-binary.

Primary care experiences

In this study, we assess the same questions as the 2018/19 NZHS[19] to compare the primary care experiences between transgender participants and the general population. We have presented the full questions for these experiences in Table 2. An option of "don't know" was provided for each of these questions and participants who selected this were treated as missing.

To identify additional issues that were not covered by the closed-ended questions, participants were asked an open-text question: "Is there anything else about your experiences with primary healthcare providers that you would like to share with us?". Participants who responded "no" were treated as non-responses, leaving qualitative comments from 153 (18%) of participants.

Analysis

Descriptive analyses of the quantitative data were carried out in IBM SPSS Statistics version 27. Using VassarStats,[20] we conducted Chi-squared goodness-of-fit tests to compare the observed proportion for dichotomous primary care experiences (unmet cost and unmet transport) of transgender participants in *Counting Ourselves* with the expected value of the general population from the NZHS. We also carried out independent sample t-tests to assess the differences in mean scores for no confidence, poor explanation, and poor decision between the two samples. Cohen's d and risk ratio estimates were used to determine the effect size differences of the negatively framed primary care experiences. General population estimates from the NZHS were for those aged 15 or older so we removed data of *Counting Ourselves* participants aged 14 years old (n=17) in these analyses. We also performed Chi-squared goodness-of-fit tests and computed standardised adjusted residuals in SPSS to identify demographic differences among participants who left qualitative comments. Residual values that exceed ±1.96 suggest the proportion of participants who responded to the open-text question versus those who did not differs significantly for the demographic group in question.

To analyse transgender people's qualitative comments to the open-text question in *Counting Ourselves*, we undertook a content analysis to identify patterned codes and group them as categories.[21] The first author was responsible for familiarising himself with the data and generating a coding schema, which involved revisiting the data multiple times. The coding schema and results were discussed among authors and any disagreements on the selected exemplars for each code and category were reviewed by the first author until a consensus was achieved. Andersen's Behavioural Model[9] for transgender people by Lerner and Robles[10] was adapted as a conceptual framework for the organisation of themes. In order to contextualise each exemplar, we note the participant's ethnicity, gender, and age group (Youth: 14–24; Adult: 25–54; Older adults: 55 and above).

Table 1: Demographic details of *Counting Ourselves* participants who have a regular GP clinic that they visit.

Age groups	**n (%)**
14–18	133 (15.3)
19–24	248 (28.1)
25–39	301 (34.6)
40–54	117 (13.4)
55+	72 (8.3)
Gender groups	
Trans women	253 (29.1)
Trans men	252 (29.0)
Non-binary AFAB	284 (32.7)
Non-binary AMAB	80 (9.2)
Ethnic groups[a]	
New Zealand European/Pākehā	734 (84.3)
Māori	112 (12.9)
Samoan	13 (1.5)
Chinese	12 (1.4)
Regions[b]	
Auckland	258 (30.1)
Wellington	245 (28.6)
Other North Island region	165 (19.3)
South Island	203 (23.7)

Note. AFAB, assigned female at birth; AMAB, assigned male at birth; GP, general practitioner.
[a] Only included ethnic groups with more than 1%. Percentage was derived using the concept of total response ethnicity where participants can be counted towards to the statistics for more than one ethnic group.[18]

Table 2: Primary care experiences of *Counting Ourselves* participants and comparisons with New Zealand Health Survey 2018/9 (age 15+).

	Counting Ourselves **2018 (mean/SD; %)**	**NZHS 2018/19 (mean/SD; %)**	**t-test/Chi-squared statistics**	**Effect size differences**
No confidence: Did you have confidence and trust in the GP you saw?[a]	1.48 (0.60)	1.26 (0.52)	t(843)=12.29, p<0.001	Cohen's d=0.39 [0.32–0.46]
Poor explanation: Thinking about your last visit to a GP, how good was the doctor at explaining your health conditions and treatments in a way that you could understand?[b]	1.75 (0.87)	1.57 (0.86)	t(825)=6.01, p<0.001	Cohen's d=0.21 [0.14–0.28]
Poor decision: How good was the doctor at involving you in decisions about your care, such as discussing different treatment options?[b]	1.86 (0.96)	1.63 (0.89)	t(825)=6.01, p<0.001	Cohen's d=0.25 [0.18–0.32] [1.03–2.22]
Unmet cost: Was there a time when you had a medical problem but did not visit a GP because of cost?[c]	38.44	17.38	χ2 (1)=11.06, p<0.001	Risk ratio=2.21 [2.11–2.32]
Unmet transport: Was there a time when you had a medical problem but did not visit a GP because you had no transport to get there?[c]	13.51	2.95	χ2 (1)=7.78, p=0.005	Risk ratio=4.58 [4.05–5.18]

Note: Weightings were applied to the 2018/19 NZHS dataset to approximate the age and ethnicity distribution of the *Counting Ourselves* participants (see Appendix 1). Among participants who responded having a GP clinic or medical centre that they usually visit (N = 871). GP = general practitioner. SD = standard deviation.

[a] = Response options were "Yes, definitely" (1), "Yes, to some extent" (2), and "No, not at all" (3).

[b] = Response options ranged from "Very good" (1) to "Very poor" (5).

[c] = Response options were "Yes" and "No" and participants were classified as having unmet need for cost or transport in the past 12 months when they responded "yes".

Table 3: Themes, subthemes, and supporting quotes from the content analysis of qualitative data.

Themes (framed by Andersen's Behavioural Model)	Subtheme	Exemplar quotes as typed by *Counting Ourselves* participants (noting ethnicity, gender, and age)
Healthcare environment (condition of primary care settings)	Gaps in knowledge or confidence about providing gender-affirming care	I think they're genuinely trying their best but underfunding, understaffing, and a general lack of training and information around gender diversity can make their jobs a lot harder. There are a few bad apples who will give me a hard time for being trans, but most people are nice and just trying to do their job. (*Other ethnicity, Trans man, Youth)*
		Although my pronouns and name are respected, there's a definite disconnect between the healthcare I receive at my GP and the healthcare I receive in my transition through other doctors (plastic surgeon and endocrinologist.) My GP simply does not know enough about trans* people to be of any help except ask others with more experience what to do, and recommend me options based off of that. It doesn't help that I am their first trans* patient. *(N Z European/Pākehā, Non-binary, Youth)*
		I teach them. I have no choice. Now, they are happy to be educated. 10 years ago, I was treated like s**t! *(NZ European/Pākehā, Non-binary, Adult)*
		If a primary health care provider lacks knowledge that is fine if they take responsibility for their own awareness raising and have an open accepting attitude with no underlying transphobia. I would rather see a less knowledgeable practitioner who is not transphobic than a practitioner who professes to have knowledge and uses this to exert power over you based on underlying transphobia i.e., has knowledge and uses this to discredit you. *(Māori, Trans man, Older Adult)*
	GPs as gatekeepers of gender-affirming care	It is expensive to see a GP (gatekeeper of NZ health system) who often dont make the referral you need. *(NZ European/Pākehā, Non-binary, Adult)*
		There have been one or two times when I've found it hard to have a conversation about my gender-affirming transition…when I try to push getting a referral somewhere my GP would brush it off. There was once or twice when she said we would talk about it at the next appointment. I did keep pushing it and now she is in the process of getting me a referral, or at least, that'd what she said to me. *(NZ European/Pākehā, Trans man, Youth)*
		I find I have to be very carefully and politely assertive to acquire medical care. My current GP is the best I've had, but I have to do the work of presenting options and convincing him of permitting medicines I need. I don't believe I would receive adequate treatment if I wasn't extremely careful with diplomacy. *(NZ European/Pākeha, Trans woman, Adult)*
	Positive experiences with primary care	I have been with my GP my entire life, so we have a good relationship. Even though my GP also sees other members of my family, at no time was I worried that they would break patient-doctor confidentiality. My GP also has other trans patients, so is able to navigate these systems quite well. *(NZ European/Pākeha, Non-binary, Adult)*
		[My healthcare providers] are wonderful, helpful, empathetic and incredibly trans friendly. They do the best they can with limited resources. They have never been unkind or transphobic to me or my partner. *(Other ethnicity Trans man, Youth)*
		My primary health care provider is very good with most of my health concerns, and respects me as a patient who is well informed and educated and involved with my treatment. *(NZ European/Pākehā, Non-binary, Youth)*
	Experiences with other staff members	Felt that there was no awareness towards the changes happening physically/mentally and that continued to treat me as 'male' - including being called by my dead name by the receptionist and nurse staff. *(NZ European/Pākehā, Trans woman, Adult)*
		Just that receptionists can really make a practice feel like an okay place to go. Or not. *(Māori, Trans man, Older Adult)*
		Receptionists can impact my experience at the GP. E.g., the GP can be great but the if the admin staff get it wrong (name/pronoun) it doesn't matter how good the Dr is. *(NZ European/Pākehā, Trans man, Adult)*

Table 3 (continued): Themes, subthemes, and supporting quotes from the content analysis of qualitative data.

Themes (framed by Andersen's Behavioural Model)	Subtheme	Exemplar quotes as typed by *Counting Ourselves* participants (noting ethnicity, gender, and age)
Predisposing characteristics (Beliefs and attitudes about primary care)	Disclosure of transgender identities	I tend not to see my GP as I feel his knowledge is too generic…I have been HIV positive for 20 years and have had the same GP for 15 years. He still knows little about HIV and hasn't taken the time to find out. For this reason I feel he'd be apathetic about gender issues. *(Māori, Non-binary, Adult)*
		I've been made to feel less by GPs without even bringing gender identity into the equation. So why would I want to share? *(NZ European/Pākehā, Non-binary, Adult)*
	Distrust towards GPs	I have had a severely traumatic experience with my previous GP who had been lying about referrals, tests, and specialist letters. It has left me unable to trust doctors as a whole, and left me terrified to speak to my current GP about gender related things. As a disabled autistic person, I have found the system to be ineffective, which then makes us push trans stuff, or gender conversations on to the back burner. *(NZ European/Pākehā, Non-binary, Youth)*
		There are certain matters I don't trust them with, both in terms of their behaviour and because I don't trust them not to record details (e.g., about my sex life or the fact that I am a sex worker) that I wish to keep private. *(NZ European/Pākehā, Non-binary, Adult)*
Enabling resources (Resources that must be present for transgender people to access care)	Affordability of care	Cost is a real barrier to care. I have been off hormones for six months because I couldn't afford to see my GP and the cost of injection at that time. I am now in the process of starting treatment again but need to save up money to see my GP. While my centre is good in terms of their experience treating trans people, their costs are very high. *(Māori, Trans man, Adult)*
		I don't go to the doctor unless I really really need to because it's too expensive. *(NZ European/Pākehā, Non-binary, Youth)*
		I currently have access to free healthcare through the university. Without this I would go to the doctors much less. *(NZ European/Pākehā, Non-binary, Adult)*
	Region and travel time	There are quite a few good trans* doctors in central Auckland, so I am very fortunate. But in outer suburban and rural areas, finding ok doctors is hard for other trans people. *(NZ European/Pākehā, Non-binary, Adult)*
		I travel 50km to see my GP and pay significantly more than I would if I had a local GP. I have this GP because I trust him completely and he is always trying to educate himself in regards to best practice. *(Māori, Trans man, Adult)*
		Because I moved to a rural area I am continuing to see my old GP over an hour's drive away as I have no faith in the local GP's knowledge and professionalism regarding trans and non-binary people. *(NZ European/Pākehā, Trans man, Adult)*

Note: Others include participants not identifying as Māori, Pasifika, Asian, and European/Pākehā, such as those identifying as Middle Eastern, Latin American and African.

Results

Differences in primary care experiences for transgender participants from the *Counting Ourselves* survey compared to the general population estimates for Aotearoa New Zealand are outlined in Table 2. We found transgender participants consistently reported higher mean scores than the general population for low confidence in GPs, poor explanations of health conditions by GPs, or poor involvement from GPs in decision-making processes. The differences in mean scores for the two samples were statistically significant. The small effect size differences (ranging from 0.21 to 0.39 standard deviation) for healthcare experiences with GPs may be encouraging findings. However, transgender participants were twice as likely to report difficulty accessing GP clinics due to cost and four times more likely to report transport barriers.

Demographics of participants who responded to the open-text question are presented in Appendix 2. We found that older participants were more likely to leave a comment, but there were no significant differences across genders, ethnicities and regions. The results of our analysis of comments about primary care reported by transgender participants are detailed in Table 3, along with supporting quotes from participants. The organisation of three themes followed the framework outlined in Andersen's Behavioural Model. Each of these themes comprises subthemes that were identified through a conventional content analysis (i.e., data-driven).[21] The first theme is the healthcare environment and includes issues relating to gaps in provision of care to transgender people, GPs as gatekeepers of gender-affirming care, experiences with other staff, and positive primary care experiences. The second theme is the predisposing characteristics that relate to transgender people's distrust towards GPs or their willingness to disclose their transgender identity. The third theme is enabling resources for access to primary care and includes affordability and travelling time.

Discussion

The analyses present in this article demonstrate that transgender participants in the *Counting Ourselves* survey are more likely to report negative experiences of primary care and barriers to accessing care compared to the Aotearoa New Zealand general population. Our accompanying qualitative analyses were framed using Andersen's Behavioural Model[9] to guide the classification of enablers and barriers to accessing primary care based on three themes, namely health search environment, predisposing characteristics and enabling resources.[10] By utilising a combination of quantitative and qualitative analyses, this paper provides new insights into individual and contextual understanding of healthcare experiences of transgender people in Aotearoa New Zealand.

Health service environment

The overall rate of negative experiences was relatively low among our transgender participants (Table 2), which expands on an earlier analysis of *Counting Ourselves* data that demonstrated participants had a mixture of supportive and unsupportive healthcare experiences.[22] However, it is notable that *Counting Ourselves* participants had significantly greater risk of not feeling confident in their GPs and greater risk of reporting that GPs were poor at explaining health conditions, when compared to general population estimates from the NZHS. Similar findings were noted in the 2018 US TransPop survey, where transgender people had a higher likelihood of reporting dissatisfaction with their healthcare relative to cisgender people.[23]

In our qualitative findings, transgender participants raised a range of issues that impact on healthcare experiences. In particular, the *Counting Ourselves* participants commented about gaps in knowledge or confidence about providing gender-affirming care among GPs and suggested that training for GPs should include clinically and culturally competent care for transgender patients. Taken together, quantitative and qualitative findings add weight to previous research demonstrating that existing curricula in Aotearoa New Zealand medical schools contain minimal content relating to gender diversity,[24] and our findings point to an urgency to address this educational gap for primary care providers.

Moreover, care for transgender people ought to reflect GPs' commitments to professionalism including awareness of cultural safety as a vital framework for their work.[25] Notably, our participants stressed the importance of having a respectful GP–patient relationship and GPs who had an openminded attitude towards learning about the health needs of transgender people. The concept of cultural safety was originally recommended by scholars to address indigenous and ethnic health inequities in healthcare settings within Aotearoa New Zealand.[26] Cultural safety requires health professionals to reflect on power structures related

to their own culture, prejudice, and privilege that may affect quality of care, and to dismantle barriers to clinical effectiveness arising from inherent power imbalances. The Medical Council of New Zealand's statement on cultural safety recognises that this extends beyond Indigenous status or ethnicity,[27] to include gender and sexual orientation as well as other population groups. The framework of cultural safety has been applied to the healthcare inequities faced by transgender people in the US,[28] to urge health professionals to recognise the context of social marginalisation among transgender people, and monitor for discrimination including microaggressions (e.g., misgendering or refusing to use language that affirms a transgender patient's gender) that may be perpetrated by providers and staff.

Transgender participants in this study expressed a preference for GPs who could demonstrate respect in understanding their health needs and provide referrals for other gender-affirming care through secondary services (Table 3). However, the presence of gatekeeping practices that compel transgender people to fulfil certain criteria prior to being granted access to gender-affirming care deterred many from accessing needed care.[1,12,13] This contrasts with current Aotearoa New Zealand guidance recommending that GPs follow an informed consent model that is culturally safe, recognises gender diversity, and working alongside patients in a flexible and responsive way that acknowledges transgender people as the experts of their own lives.[1,28] In an informed consent model, GPs may explore a transgender person's gender experience and history to clarify the person's goals, but the primary objective is to provide sufficient information to guide patients' decision-making about any desired aspects of gender-affirming care.[1]

Predisposing characteristics

Transgender participants described negative experiences with not only GPs but also other staff at a GP clinic such as receptionists and nurses. Transgender people's beliefs and attitudes about using primary care are influenced by their previous interactions with primary care providers.[10] Our findings uncovered higher levels of transgender participants rating GPs as poor at explaining health conditions and involving them in decision about care; international research has found evidence that these negative experiences can lead to avoidance of the health care system.[10] Many participants expressed distrust and decreased motivation to disclose their transgender identities when they encountered GPs who demonstrated low levels of cultural safety about transgender people. This has implications when transgender people are reliant on GPs for referrals to gender-affirming care, or if transgender patients do not feel comfortable disclosing information about previous gender-affirming healthcare interventions that may be relevant to their ongoing health.

Enabling resources

Our qualitative findings showed enabling resources such as affordable cost and low travelling time were not always readily available for transgender participants. Likewise, our quantitative findings revealed cost and transport as notable barriers to accessing primary care, with transgender participants having about three to five times greater risk than the general population of reporting an unmet need for GP visits due to these barriers. A recent study with transgender people at a primary care clinic in Wellington found that improving the accessibility of primary care (e.g., low cost and close-to-home services) allowed transgender people to focus on making healthcare decisions and not to worry about resource issues.[14] While some of our participants chose to incur the cost of travelling long distances to access a GP with greater transgender cultural safety, this was not a financial option for others. This reinforces that affordability and accessibility are necessary but not sufficient if GPs are not competent in delivering gender-affirming care. Our evidence speaks to the need for more resources and training for all staff working in primary healthcare settings, including receptionists, administrative staff, nurses and GPs, to improve their confidence and competence in delivering culturally safe care to their transgender patients.[10]

Overall, Andersen's Behavioural Model for transgender people[10] served as a useful conceptual framework to explain how healthcare use among transgender people in Aotearoa New Zealand is affected by contextual factors that create barriers or are enablers of care. However, as access to equitable healthcare is also influenced by other predisposing characteristics such as age, ethnicity, region, and disability status,[10,11] future research should examine if there are additional barriers preventing some transgender people from accessing healthcare and building a culturally safe relationship with healthcare providers here. While the model also assesses clinical need of care (i.e., whether people feel they have a need

for care) as an individual-level factor predicting healthcare use,[10] this was not a prominent theme for our transgender participants. It may be that the framing of our open-text question meant that participants who had not utilised GP services refrained from leaving a comment or that participants identified contextual barriers as more concerning factors for healthcare use.

There are some limitations that need to be borne in mind when considering the generalisability of our cross-sectional findings to the wider transgender population in Aotearoa New Zealand and beyond. The convenience sampling design of the *Counting Ourselves* survey meant that the study may have been less accessible to transgender people without reliable internet access and those without connections to transgender communities. There was presence of a response bias for open-text responses by age group: older participants were more likely to provide a comment. A higher proportion of younger participants responded to the *Counting Ourselves* survey (i.e., 65% aged between 14–29) so their particular barriers and enablers to accessing relevant aspects of healthcare have been measured well in the quantitative data.[17]

Conclusion

Like many countries, the majority of health care in Aotearoa New Zealand is provided in primary care settings and these settings are the first point of contact for most healthcare outside of emergency situations. It is crucial to create primary care services which are culturally safe so that all transgender people feel welcome.[26,28] This requires all primary healthcare professionals to have basic knowledge about providing appropriate gender-affirming care, to counter power differentials in provider–patient interactions including by avoiding gatekeeping, and to promote acceptance of gender diversity in every healthcare setting. Improvements could include training all clinic staff, including reception staff, using people's correct names and pronouns, and understanding local pathways for gender-affirming healthcare.

A small but increasing number of GPs in Aotearoa New Zealand are gaining the knowledge and experience to prescribe gender-affirming hormone therapy under an informed consent model in primary care.[1,29] This is a positive move for gender-affirming healthcare, which we hope to see expanding further in the future. For this to become more widespread, support for GPs is needed in the form of adequate funding, time provision and education. Future research exploring GPs' provision of gender-affirming care could explore transgender people's experiences with GPs who have trained to directly provide different aspects of care such as initiation of gender-affirming hormones in addition to continuation of prescriptions started by specialists. We recognise that not all GPs will want to initiate gender-affirming hormones, but it is expected that all GPs are competent to provide ongoing repeat hormone prescriptions and need adequate information to provide this safely. Our results show that transgender people's experiences of primary care would be improved even with a more foundational upskilling for GPs about transgender people's health care needs. Central to Aotearoa New Zealand's Health Strategy is ensuring the health system works for every person living in Aotearoa New Zealand, and that barriers to equity can be removed.[30] The current health system is not working equally for transgender people, and primary care has a key role to play to reduce these inequities.

COMPETING INTERESTS
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Appendix 1: Weightings applied to the New Zealand Health Survey 2018/19 to match the age and ethnicity distribution of the *Counting Ourselves* sample.

Age	Pākeha/NZ European	Māori	Pasifika	Asian
15–19	17.6/4.2=4.19	2.9/1.5=1.93	0.3/0.9=0.33	0.6/1.4=0.43
20–24	18.2/4.9=3.71	3.8/1.4=2.71	1.0/0.7=1.43	1.0/1.6=0.63
25–34	21.7/9.8=2.21	3.6/2.5=1.44	1.4/1.2=1.17	1.6/4.0=0.40
35–44	7.9/9.1=0.87	2.1/2.1=1.00	0.5/1.2=0.42	0.5/2.9=0.17
45–54	6.5/11.6=0.56	1.2/2.0=0.60	0.2/0.8=0.25	0/1.9=0
55+	6.3/28.7=0.22	1.0/2.2=0.45	0.1/1.1=0.09	0/2.3=0

Weightings were obtained using the formula.

Appendix 2: Demographic details of participants who provided a response in the open-text box.

	Responding n (%)	Adjusted standard residual
Age groups		
14–18	11(7.5)	-3.1
19–24	27(10.1)	-3.2
25–39	70(21.3)	3.1
40–54	24(19.8)	1.1
55+	21(27.3)	2.7
	$\chi2$ (4)=30.06, p<0.001	
Gender groups		
Trans women	34(12.3)	-2.0
Trans men	54(20.1)	2.1
Non-binary AFAB	47(15.5)	-0.4
Non-binary AMAB	16(17.8)	0.5
	$\chi2$ (3)=6.35, p=0.096	
Prioritised ethnic groupsa		
Māori	22(18.3)	0.7
NZ European/Pākehā	122(16.6)	0.6
Others	9 (10.3)	-1.6
	$\chi2$ (2)=2.69, p=0.261	

Appendix 2 (continued): Demographic details of participants who provided a response in the open-text box.

	Responding n (%)	Adjusted standard residual
Regions		
Auckland	43(15.1)	-0.6
Wellington	46(17.6)	0.7
Other North Island regions	32(19.5)	1.3
South Island	29(13.5)	-1.2
	$\chi 2$ (3)=3.11, p=0.376	

AFAB, assigned female at birth; AMAB, assigned male at birth.
Note: [a]We applied a prioritisation of participants into one of the four ethnic groups in a priority order of Māori, Pasifika, Asian, and NZ European/Pākehā or other.[22] Due to low number of responses for Asian, Pasifika, and MELAA participants, we collated these into "Others".
Residual values that exceed ±1.96 suggest the proportion of participants who responded to the open-text question differs significantly for the demographic group in question.

Smokefree and vapefree streets: high levels of support from tourists, residents and businesses, implications for tourist-destination communities in New Zealand

David Brinson, Charlotte Ward, Cheryl Ford, Annabel Begg

ABSTRACT

AIMS: To (a) evaluate the attitudes of local businesses, residents, and visitors regarding the trial of a voluntary smokefree and vapefree zone covering the central business streets of a popular tourist town in the South Island of New Zealand, and (b) observe smoking and vaping prevalence before and during the trial, to inform national and local smokefree environment advocacy work.

METHODS: The six-month smokefree and vapefree trial included an embedded mixed methods project evaluation to capture a range of stakeholder groups' views about the smokefree and vapefree zone. Data collection methods included face-to-face interviews, non-random pen and paper and online surveys, and observational scans. Qualitative data were analysed using a systematic iterative thematic approach, and simple descriptive quantitative analyses were applied to the survey data.

RESULTS: The analysis synthesised information from almost 1,000 respondents. A large majority of respondents supported smokefree and vapefree within the zone (visitors 84%; residents 67%; businesses 63%). A majority of responding visitors indicated that the same rules should apply to both smoking and vaping and that they would be either *more likely* or *as likely* to visit other tourist destinations in New Zealand if they had smokefree and vapefree zones. Implementing the initiative was associated with a reduction in the number of people visibly smoking and vaping within the zone.

CONCLUSION: The weight of evidence from the project evaluation points towards a net benefit both for individuals and for the community from implementing voluntary smokefree and vapefree zones in tourist destinations in New Zealand.

Tobacco smoking remains a major cause of death and disability around the world, as well as a major contributor to health inequities.[1] Many countries have progressively implemented strong tobacco control policies and legislation to protect present and future generations from the considerable health, economic, social, and environmental impacts of tobacco.[1] In New Zealand, the Smokefree Environments Act 1990 was passed to "reduce the exposure of people who do not themselves smoke to any detrimental effect on their health caused by smoking by others"[2] and to regulate and control the marketing, advertising, and promotion of tobacco products. Legally-designated smokefree indoor spaces now have wide public and political support in New Zealand.[3,4] There is also growing interest and support for social denormalisation strategies, including the adoption of smokefree outdoor spaces; such as parks, playgrounds, and other public spaces.[4] Denormalisation strategies are designed to influence social norms and modify addictive nicotine-use behaviours (including vaping).[4,5] Denormalisation involves changing tobacco/nicotine use from acceptable and desirable to unacceptable and undesirable, across a broad range of settings.[3] Decreasing the social acceptability of smoking has been shown to be a highly effective policy tool in reducing consumption.[5]

However, the effectiveness of denormalisation strategies has been challenged in recent years by the emergence of increasingly sophisticated electronic nicotine delivery systems (ENDS) — most commonly, e-cigarettes.[5] There has been protracted debate about the regulation of vaping in spaces where conventional cigarettes are currently prohibited. Vaping legislation was not introduced in New Zealand until 2020, prohibiting vaping on aircraft, and inside workplaces, schools, early childhood centres, and some other indoor public spaces (the legislation does not cover outdoor spaces).[6] In addition, progress in

translating smokefree and vapefree outdoor rules into national policy has been limited, leaving sub-national jurisdictions to enact rules or bylaws on a case-by-case basis.[7,8]

Whilst many councils across New Zealand have implemented smokefree outdoor spaces to some degree, the extension of these policies into business areas and the adoption of vapefree outdoor spaces is still limited.[7,8] Most examples of these initiatives have employed facilitative and promotional approaches and these initiatives primarily rely on signage and communication to build public support and promote compliance.[7] Despite the voluntary nature of New Zealand's outdoor smokefree strategies, this approach can still arouse concern and resistance from some stakeholders. For example, some business owners may have concerns about economic harms, despite studies of smoking bans in the hospitality sector showing no overall substantial economic gains or losses[9–11] and such bans have been found to be popular with customers.[12]

Hospitality and tourism are important sectors for New Zealand and insufficient work has been done to investigate how acceptable smokefree and vapefree outdoor policies are to our domestic and international visitors. The aim of this mixed methods evaluation study was to obtain current information on the attitudes and level of support from visitors, residents, and businesses, for a smokefree and vapefree zone covering the central business streets of a New Zealand tourist town. The study also aimed to see if there were changes in observable smoking and vaping behaviours over the trial period (the study did not aim to demonstrate a change in the proportion of regular smokers/vapers within any group or over time).

To our knowledge, this is the first formal evaluation of a smokefree and vapefree zone simultaneously applied to the entire central business area of a tourist town in New Zealand (i.e., where there were no policies prior). The study also evaluated any reported impacts on stakeholders, including the hospitality and tourism-focused businesses that engaged with the evaluation interviews. This information may be helpful to local government authorities when considering whether public spaces adjacent to retail and other business premises can and should be both vapefree and smokefree.

Methods

This evaluation study used mixed methods to assess stakeholders' experiences, perspectives, and attitudes towards the smokefree and vapefree zone trial. Broadly, the methods included online surveys, phone surveys, scheduled face-to-face interviews, public intercept surveys, pen and paper feedback cards, and field observations of smoking and vaping behaviours.

Intervention

Breathe easy in Hanmer Springs was a six-month trial of a smokefree and vapefree zone implemented across key public spaces, including the street frontage of the retail/business area of the village. The setting was Hanmer Springs, a popular tourist town in the South Island of New Zealand (population 960 in 2018; regular smokers 12.6%, 2018; 216,311 guest nights in the wider Hurunui District, with 33% international, 2018–2019 year).[13,14] The voluntary initiative was supported by signage and a communication plan. The aim of the communication plan was to raise public awareness of the initiative and to help empower the public to provide positive social reinforcement if smoking behaviours were observed in the zone. The majority of promotions were initiated at the launch of the trial (14 February 2019). A limited amount of reporting on the impending trial was seen in local and national print, online, and radio media in the months preceding the trial. The signage (placed just prior to the start of the trial) included one main display board/map and a range of metal and self-adhesive signs and posters, attached to all public picnic furniture, selected curbside poles, public toilet cubicles, council owned rubbish bins, and other public fixtures as suitable within the trial zone. Businesses were not required or requested to actively implement the no smoking/no vaping policy or messaging (although some may have done so to varying degrees).

Sample

Potential respondents were selected from three stakeholder groups within a specific geographical setting (a convenience sample). The three stakeholder groups were the local businesses (owners/managers), residents (or property owners/rate payers), and visitors to the township (both domestic and international). The recruitment of business owners/managers was via email and phone using contact information that had been compiled by a health promoter over the two years prior. Owners'/managers' contact details were collated from lists provided by the local Business Association, and listings in local advertising and business directories, or displayed on premises within the village (if not identified via previous

methods). The characteristics/classification of the recruited business respondents were: accommodation (n=15); hospitality (n=9, representing 13 businesses); retail (n=18, representing 21 businesses); tourism/outdoor activity (n=6); trade/service provider (n=6). Visitors were sampled via two methods: (1) random in-person point-intercept interviews on the streets within the zone; and (2) feedback cards placed at accommodation providers around the village. In total, 22 out of 38 identified accommodation providers agreed to include feedback cards in their guest room compendiums including motels, hotels, rental homes, backpackers, camping grounds and B&Bs (unlisted B&B and Airbnb were excluded). Residents were sampled via two methods: (1) random in-person point-intercept interviews on the streets within the zone; and (2) via invitations to engage online, including a URL link posted to a closed village social media group, QR codes on posters/signs within the zone, and via URL links posted in the local school and village newsletters.

Measures were put in place to reduce the possibility of multiple written responses (ballot stuffing) and multiple/duplicate online submissions (acknowledging that, with effort, these measures could have been circumvented). Firstly, manual scans were used to detect obvious duplication of tourist responses within each batch of handwritten response cards retrieved from each accommodation provider (one instance was detected, and copies removed). Secondly, the online survey platform collector settings used IP address to limit responses to one response per device.

Procedure

A base questionnaire (see Appendix) was drafted by the project team and peer reviewed by a public health physician. The base questionnaire included a core set of policy-relevant questions to be asked of all respondents. The central question assessed respondents' level of support for the zone being specifically smokefree *and* vapefree (i.e., a vote in principle for vaping and smoking to be treated the same/differently with respect to outdoor public areas). The questionnaire also included questions on awareness of the zone and support for the zone becoming permanent (as implemented in the specific context of Hanmer Springs). In the interest of brevity, these secondary questions are not reported here. The base questionnaire did not include demographics, as the evaluation study was not intended to have enough statistical power to perform sub-group analyses (including smoking/vaping vs non-smoking/non-vaping).

The base questionnaire was then tailored to the different stakeholder groups by adding supplementary questions that explored different stakeholder perspectives and experiences (e.g., any impacts on business, tourists' likelihood to visit other smokefree and vapefree tourist destinations, and residents' perspectives). The questionnaire format was also optimised for use online, for pen and paper completion, and to suit a semi-structured face-to-face interview format.

The semi-structured interview schedules for use with the business representatives (see Appendix) were the most in-depth questionnaires. The interview schedule was developed using an applied qualitative research approach[15] whereby the questions were shaped by the information requirements of the stakeholders, as apparent from a prior scoping/consultation one year earlier.[16] The two interviewers (a Public Health Analyst and a Health Promoter, both from Community & Public Health, Canterbury DHB) used role play to practice and refine the interview schedule and feedback was provided by a third assessor (another Public Health Analyst, also from Community & Public Health, Canterbury DHB). The interviews with business representatives typically lasted 30 minutes and included open-ended questions and probes. The questions asked for detailed information about any effects of the zone on businesses' operations and staff. All respondents were also given the opportunity to provide one open response on any aspect of the smokefree and vapefree trial. The business interview settings included retail and hospitality premises, accommodation providers, and other recreational and outdoor adventure providers.

The face-to-face interviews with members of the public were facilitated by a Health Promotion Advisor from the Cancer Society, Canterbury West Coast Division, and three volunteer research assistants also provided by the Cancer Society (the volunteers undertook a site orientation and training session on the day). These interviews were conducted on public streets within the trial zone. All interviews and surveys were undertaken between 14 February and 18 July 2019.

The observations employed multiple four-minute scanning cycles, based on the methods developed by Thomson and colleagues.[17] Specifically, observations of the smoking and vaping behaviours of those who appeared to be over 12 years old (and who are inclined to smoke/vape in public on the street) were made across four defined 10–20m^2 sites within the smokefree and vapefree zone. Note that age 12 is a methodological classifi-

cation not a legal classification, as used in Thomson and colleagues' established observation protocol.[17] The observations were undertaken by two observers (from the Cancer Society, Canterbury West Coast Division, having undertaken specific training/field trials focused on minimising inter-observer bias). The observations were conducted over five weekend days, in two periods (daytime only, as the policy is in large part about denormalisation and modelling smokefree and vapefree to young people). The pre-intervention observations were conducted just prior to the introduction of the trial on February 14th (Valentine's Day). Hanmer Springs visitor numbers peak noticeably on weekends and school holidays and the "family friendly" attractions in Hanmer Springs draw large numbers of families. The high proportion of children typically present in the village during the school holidays and during the weekends may influence adults' smoking and vaping behaviours (downwards),[18–22] therefore, all of the observation times were scheduled to provide a similar context (school holidays–weekends) for all observations. Additional observations comprised set walking loops and between site observations for the general monitoring of tobacco litter, any observed displacement of smokers/vapers to out-of-zone areas, and/or any other unanticipated effects.

Analysis

Qualitative data were analysed using a systematic iterative thematic approach to identify recurring patterns, following the method described by Pope and Mays and others.[15] The multi-choice and three-point Likert scale questionnaire (Appendix) responses were extracted from the different iterations of the surveys/interviews and the proportion of respondents in agreement with the various statements were calculated for each stakeholder group. Some respondents did not answer all questions and percentages were calculated excluding missing responses. The observational data (smoking and vaping behaviours) were analysed by means of Chi-squared tests (using SAS version 9.4, SAS Institute Inc., Cary, NC) to determine any differences in the observed smoking and vaping behaviours between baseline and follow-up.

Ethics

It was determined that this evaluation did not meet the criteria triggering a need for Health and Disability Ethics Committee review. The evaluation was considered low risk as it did not involve the collection of health information, age, gender, or ethnicity, and the responses were confidential and anonymous. Those invited could decline to participate, or choose not to answer any particular question, if they wished.

Results

Participants

In total, 956 individuals provided responses to the surveys, comprising 680 visitors, 222 residents, and 54 business representatives (Table 1). Of the 956 responses, 548 were completed via pen and paper feedback cards, 211 were completed face-to-face, and 197 were completed online. Most of the visitors' responses were collected via the pen-and-paper feedback cards (n=548 out of 680 visitor responses) with an additional 132 visitors having provided information via face-to-face interviews on the street. Most of the residents' responses were collected online (n=166) with an additional 56 residents interviewed on the streets within the smokefree and vapefree zone (total n=222 residents).

The response rate for businesses was approximately 36.5% (54 of 148 identified eligible businesses invited to participate). The response rates for the face-to-face interviews on the street, the residents' online surveys, and the visitor feedback cards could not be calculated as the denominators were not known.

Key findings

Visitors

Overall, 84% (n=568) of responding visitors indicated that they supported the zone being both smokefree and vapefree (83%, n=118 International and 84%, n=450 Domestic visitors). A further 8% (n=53) of responding visitors indicated vaping should be allowed in the zone (but supported smokefree) and 9% (n=59) indicated both vaping and smoking should be allowed in the zone (i.e., didn't support the zone) (Figure 1). Further, 54% of responding visitors (n=297) indicated that they would be more likely to visit other places with smokefree and vapefree zones, 40% (n=220) indicated no preference, and 6% (n=30) indicated that they would be less likely to visit other places with smokefree and vapefree zones. Overall, 95% of responding visitors said they would be more likely or as likely to visit other places in New Zealand that have no smoking/no vaping zones (97%, n=111 International and 94%, n=406 Domestic

visitors). International visitors tended to indicate similar levels of support for the zone compared with domestic visitors. Approximately 150 visitors also provided either written or verbal comments regarding their experiences and opinions on voluntary smokefree and vapefree outdoor spaces (summarised in Table 2).

Residents

Overall, 67% (n=138) of the resident respondents indicated that they supported the zone being both smokefree and vapefree. A further 6% (n=12) indicated vaping should be allowed in the zone (but supported smokefree) and 27% (n=55) indicated both vaping and smoking should be allowed in the zone (i.e., didn't support the zone) (Figure 1). In addition, the respondents provided 115 comments about their level of support for the zone or about different aspects of smokefree and vapefree regulation generally (summarised in Table 2).

Businesses

Overall, 63% (n=34) of 54 respondents from businesses indicated that they supported the zone being both smokefree and vapefree. A further 4% of responding businesses (n=2) indicated vaping should be allowed in the zone (while supporting smokefree) and 32% (n=17) indicated both vaping and smoking should be allowed in the zone (i.e., didn't support the zone) (Figure 1). One respondent was undecided. Most respondents from this group reported that the trial had no overall effect on their business, including no notable effects on customer numbers, spending patterns, or customer feedback (*no change*, 70%, n=37; *a positive effect*, 13%, n=7; *a negative effect*, 17%, n=9). Most respondents from this group also reported that the trial had no notable negative effects on staff (*no effect* 87%, n=45; *yes an effect* 14%, n=7). The business owners and managers were also asked for their general opinion of the smokefree and vapefree zone and for any final comments on the zone's effects or relevance to their business. In total, 80 responses were evaluated, including 53 general opinions and 27 business-related comments (summarised in Table 2).

Observations

The implementation of the smokefree and vapefree zone was associated with a quantifiable reduction in smoking and vaping behaviours within the designated area. The baseline observations showed a combined observed smoking/vaping point prevalence of 1.9% (of 3,355 people over 12 years old observed for up to four minutes, there were 3,292 non-smoking/vaping; 58 who were smoking; five who were vaping). This declined to 0.4% (of 3,740 people over 12 years old observed for up to four minutes, there were 3,725 non-smoking/vaping; 13 who were smoking; two who were vaping) post-implementation ($p<0.001$). Across the two observation periods, there were 10 hours and 46 minutes of field observations and a total count of 7,095 people over 12 years old. Approximately 20% of all passers-by were children (those judged to be 12 years or under). No obvious displacement effects (i.e., smokers/vapers simply moving somewhere else) or socially disruptive behaviours were observed.

Discussion

The evaluation findings provide information on the feasibility of implementing smokefree and vapefree outdoor area policies in tourist-destination communities. This study indicates that smokefree and vapefree zones such as this can be implemented and are acceptable to most stakeholders. Given the voluntary nature of the policy, acceptability would appear to be important for successful implementation/up-scaling. This study, and others,[18,19,22] indicate that zones such as this can change people's behaviour so that there is less observable smoking and vaping within a defined outdoor public area (although we do not claim to have established causality, only that the observed point estimate at baseline was statistically different to the observed point estimate at follow-up). There was also no observed displacement of smokers or vapers to out-of-zone areas, or anti-social behaviours, or other unanticipated effects noted.

This evaluation indicates support for smokefree and vapefree outdoor areas, particularly from tourists (including international tourists) and residents. Overall, a clear majority of the nearly 1,000 non-random respondents supported the implementation of the smokefree and vapefree zone as applied to the central business streets of a small tourist town (including, that the same rules be applied to smoking and vaping). The results indicate a supportive majority in each of the three stakeholder groups studied: businesses, residents, and notably, visitors. Understandably, some business owners and residents in tourist towns may be concerned that smokefree and vapefree outdoor areas will pose a deterrent to visitors. However, these evaluation findings suggest the opposite. Most respondents from the business

Table 1: Number or respondents by stakeholder group and data collection method.

Group	Survey method	Number of respondents
Visitors	**Feedback cards***	**548**
	Face-to-face on the street	132†
		680‡
Residents	**Face-to-face on the street**	**56**
	Online, linked via social media group	145
	Online, linked via community newsletters	21
		222
Businesses	**Face-to-face interview**	**23**
	Online, via personalised email link	31
		54
Total	548 pen-and-paper + 211 face-to-face + 197 online	956
Observations	Conducted over four sites and two time-points (January and April 2019)	10hrs 45min

* Visitor responses collected via feedback cards placed in the receptions and compendiums of 22 participating accommodation providers within the village (including hotel, motel, bed & breakfast, backpacker, and camping).
† 104 domestic and 28 international visitors were interviewed face-to-face on the streets.
‡ 537 domestic + 143 international visitors.

Figure 1: Respondents' support for the zone being both smokefree and vapefree, smokefree only, or neither smokefree or vapefree, by stakeholder group.

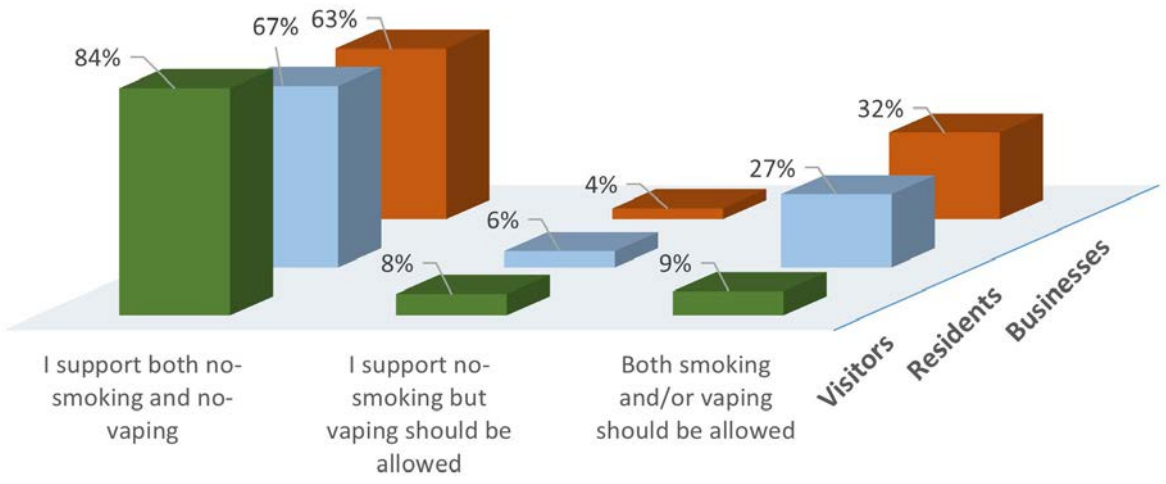

Table 2: Summary of qualitative findings, by stakeholder group.

	Supportive responses	**Unsupportive responses**
Visitors	Overall, most of the visitors' comments were supportive of the smokefree and vapefree zone, including that smoking and vaping should be regulated in the same way with respect to public outdoor spaces. Respondents noted the health risks related to second-hand smoke, and the annoyance caused by smoking and vaping. Respondents also commented on the potential for vaping to model addictive behaviours to children.	A small number of visitors' comments were unsupportive, and these generally referenced issues of individuals' rights and freedoms.
e.g.	Vaping is "interfering with others' space"; "intrusive to others"; [regarding vaping] "Kids copy what adults do ..."	"nana state"; "totalitarian state"; … [vapers should] "just be respectful to others."
Residents	Overall, most of the comments were supportive of the smokefree and vapefree zone and typically focused on the collective good, rather than on individuals. Residents placed value on the concept of smokefree and vapefree as a marketable point-of-difference for the village. Applying the same rules to both activities was seen to simplify the policy and guard against vaping "taking off".	A small number of residents submitted strongly oppositional responses, characterised by declarations about individual freedoms and the curtailment of individual rights and liberty.
e.g.	"It is what is best for the community not the smokers"; "being seen as a smokefree destination"; [the idea of] "clean, fresh, mountain air".	"If it's not illegal, it shouldn't be banned." "Freedom of choice."
Businesses	Most of the business representatives considered the zone to be a net-positive for the village. Respondents also commented that non-smokers should be able to enjoy the outdoor public spaces and not be exposed to the by-products of smoking and vaping. Business respondents also emphasised the desire for ongoing strengthening of smokefree and vapefree policy in the village.	There was concern expressed by some business representatives that local businesses might be disadvantaged by the zone, compared with businesses in tourist destinations that do not have similar smoking and vaping restrictions.
e.g.	"Good concept. Need to be realistic about timeframes to become 'normal', stick with it! Long-term"; "I think it's fantastic." "People should be able to enjoy our outdoor spaces with fresh air."	"We now have serious competition from other areas in the South Island and cannot afford to be picky on who comes here"; "dictating to people"; "restricting individual choice".

group reported that the trial had no overall effect on their business, including no notable effects on customer numbers, spending patterns, or customer feedback. The support for the trial, in turn, led the Council to adopt the policy as an ongoing initiative, and hence the streets within the central district of the village now model the denormalisation of tobacco products.

Decreasing the social acceptability of smoking (denormalisation) has been shown to be an effective policy tool in reducing consumption.[4,5] These favourable results should provide reassurance to other local authorities that implementing smokefree/vapefree policies is feasible and is generally viewed favourably by most stakeholders. As with many policy decisions, the argument for smoking and vaping restrictions requires a weighing of the pros and cons and consideration of how the effects impact on different individuals.[23–25] Several themes relating to the ethics of denormalisation strategies, smokers' preferences, and issues of freedom and autonomy, have been discussed at length in the literature[26–28] and are not discussed in detail here. However, it is important to acknowledge that while some groups may experience a wellbeing gain from the implementation of a smokefree/vapefree zone (e.g., by averting substantial health losses), others' wellbeing might be negatively affected (e.g., loss of enjoyment, stigmatisation). Individuals and groups may weigh the benefits and potential costs of restrictions differently.

This evaluation suggests that the introduction of smokefree and vapefree outdoor policies in tourist areas in New Zealand can reduce how often young people see smoking behaviours. This can contribute to denormalisation (and by extension reduce initiation) and help provide a more supportive environment for those trying to quit. Considering the low-cost nature of policies such as these,[1] the high support among different stakeholder groups, and no reported impacts on the hospitality/tourism providers, we conclude net positive effects are possible, over the long term, which will support New Zealand's smokefree 2025 goal and ultimately benefit public health.

This study is based on survey responses from business owners/managers, visitors and residents of a small tourist village in the South Island of New Zealand who agreed to participate in the evaluation. It is possible that some differences in views exist between those who chose to provide feedback and those who did not. The question of representativeness is relevant because this paper aims to provide reassurance to other local authorities that implementing smokefree/vapefree policies is feasible and is generally viewed favourably by most stakeholders. Considerable effort was directed towards accurately measuring support for the initiative in Hanmer Springs by seeking opinions from a broad range of stakeholder groups via a variety of survey methods. While the potential for response bias and/or mode effects cannot be discounted, the sampling and survey methods provided several accessible anonymous channels for individuals to provide feedback. Without any evidence to the contrary, we suggest that those opposed to the initiative or in support of the initiative were, on average, similarly able to speak up. Furthermore, our estimates of support for a smokefree and vapefree zone are high, consequently, any non-response bias would have to be very substantial to change the conclusions and implications of our study. Some differences in the characteristics of the language used across some response modes were noted (e.g., notable aggression in some survey responses linked via social media) but these differences could not be quantified, and no allowances were made in the analysis. Future initiatives may need to be adjusted/scaled for towns and cities with varied CBD size, layout, and amenity characteristics, and these factors should be considered when tailoring future intervention designs.

Conclusion

This study provides affirming information on the feasibility of implementing smokefree and vapefree outdoor area policies in tourist-destination communities. Smokefree and vapefree zones across key public spaces in retail/business areas can be implemented and are likely to be acceptable to most stakeholders. We conclude that net positive effects are possible over the long-term, that will support New Zealand's smokefree 2025 goal.

COMPETING INTERESTS
Nil.

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Appendix

Core questions [i.e., common across stakeholder groups]

Q1: Which option below applies to you?

- Resident
- Visitor from NZ
- Visitor from overseas
- Other (please specify)

Q2: Are you aware of the Smokefree and Vapefree zone in Hanmer Springs?

- Yes
- No

If yes, how did you become aware of the zone?

Q3: The next question is asking your opinion on the Zone, that is, whether you think that the Zone should be Smokefree and Vapefree (or neither).

- I support the zone being both smokefree and vapefree
- I support smokefree but vaping should be allowed in the Zone
- Both smoking and vaping should be allowed in the Zone.

Comments (if any):

Q4: Should the Smokefree and Vapefree Zone in Hanmer Springs become permanent?

- Yes
- No
- Comment (why/why not/other):

Q5: Do you smoke? YES/NO

Q6: Do you vape? YES/NO

Additional questions specific to Visitors [those providing written or verbal responses]

New Zealand is working towards making many more key public spaces and tourist spots no smoking /no vaping zones. Would you be more or less likely to visit other places in New Zealand that have no smoking/no vaping zones?

- Less likely to visit
- No difference
- More likely to visit

Additional comments welcome:
Are you:

- An international visitor
- A domestic visitor

Business Survey

Name of business:
Type of business:
Q1: What is your role here?

- Owner
- Manager
- Owner/manager
- Staff member

Q2: What do you think about the Smokefree and Vapefree Zone in Hanmer Springs?

2b: The next part is asking your opinion on the Zone, specifically, whether you think that the Zone should be Smokefree and Vapefree (or neither). We are especially interested to know which of these responses best fits your view.

- I support the zone being both smokefree and vapefree
- I support smokefree but vaping should be allowed in the Zone
- Both smoking and vaping should be allowed in the Zone

Q3: What feedback have you received from customers about the Smokefree and Vapefree Zone?

Q4: We're also interested if the Smokefree and Vapefree Zone has meant anything different for your (this) specific business, or for staff? This question has three parts to it, so we'll work our way through it.

(a) – Has the trial of the Smokefree and Vapefree zone influenced how you conduct your business? We've listed some obvious choices, but you'll also have a chance to tell us any we haven't thought of.

Has the trail encouraged you (the business/ business owners) to:

- go fully smokefree YES NO N/A
- extend outdoor seating YES NO N/A
- extend designated smoking areas to further accommodate guests YES NO N/A
- do anything else differently YES NO N/A

(b) – Has the Trial had effects on staff (again this specific business)? e.g., have staff received (or had

to deal with) any comments or complaints, or challenges from customers?

- Yes
- No

If yes, what were some of the effects?
(c) – Are there any staff who smoke or vape?

- Yes
- No

If yes, has the zone changed where or when they smoke (or anything else)?

Q5: If you consider your own (this) specific business now – what difference do you think the Smokefree and Vapefree Zone has had on your customer numbers and/or behaviours? (if any)
(a) – any influence on customer numbers"?

- Yes
- No

And note any evidence or strength of evidence, i.e., are written records produced, and/or are other explanations provided?
Comments:

(b) – any effect on customer behaviours? [e.g., stay longer/shorter, indoors/outdoors, spend more/less].

- Yes
- No

Comment (note any evidence provided, if any):

(c) OVERALL (considering your customer numbers and behaviours together), how would you describe any difference (effects/changes to the business) since the start of the Trial?

- No change
- Positive effect
- Negative effect

Q6: Since the trial has started, have you noticed any difference in the number of people smoking and/or vaping in the street outside this business (i.e., from what you can see from here)… or anything else about where and when people smoke?

Q7: In this final question, we are interested to gauge the level of support for the Zone to becoming permanent… so for our evaluation, we are asking this from a business perspective in this case… so… should the Smokefree and Vapefree Zone in Hanmer Springs become permanent?

- Yes
- No
- Comment (why/why not/other)

Do you have any last comments?

Utility of data linkage for orthopaedic service planning in the paediatric population with cerebral palsy at Starship Children's Hospital

Wendy He, Alexandra Sorhage, Nichola C Wilson, N Susan Stott

ABSTRACT

AIMS: To determine the accuracy of orthopaedic surgical procedure coding (ICD-10-AM/ACHI/ACS) for children with cerebral palsy (CP) at Starship Children's Hospital, use data linkage with the New Zealand Cerebral Palsy Register (NZCPR) to obtain demographic and clinical information for children with CP requiring orthopaedic surgical services in the Auckland District Health Board catchment area, and to determine if trends in the clinical and demographic data are useful for future service planning for children with CP.

METHODS: Surgical admission data for children with CP aged 0–18 years at the time of their first procedure were extracted from Auckland District Health Board records for 2013–2018, and information on demographics and Gross Motor Function Classification System level were obtained from the NZCPR. The ICD-10-AM/ACHI/ACS codes for surgery/intervention were matched with the operation notes in the electronic health records using NHI numbers and assessed for accuracy.

RESULTS: During the study period, 261 paediatric patients with CP underwent orthopaedic procedures, which could be grouped broadly into five categories (spine, upper limb, lower limb, Botulinum-A toxin injection only, and other) with a coding accuracy of 95%. Clinical and demographic data could be obtained from the NZCPR for 232 (88.9%) of the 261 patients.

CONCLUSIONS: Using orthopaedic surgical procedure codes, we could identify broad categories of procedures received by children with CP and the demographic and clinical characteristics of these children, which will assist with service planning and identify trends in care delivery.

Cerebral palsy (CP) is an umbrella term used to describe a group of permanent disorders of movement and posture that occur in the developing foetal brain.[1] Patients with CP have ongoing activity limitations and require multiple clinical services over a lifetime, particularly during childhood and adolescence. Information regarding the types and frequency of procedures performed in these children and knowledge of their demographic and clinical profiles would be helpful for service planning, including theatre space and rehabilitation needs, and ensuring consistency of health service delivery and outcomes.

Data linkage involves using a common link between different databases/coding systems to match up clinical information for analysis. An example is linkage using PREDICT software, which prospectively links data collected by general practitioners in New Zealand to assess patients' risk profiles for cardiovascular disease to nationwide International Classification of Diseases (ICD) coded hospitalisation and mortality databases to identify prognostic predictors based on a New Zealand cohort.[2] Data linkage affords an opportunity to make the most out of information stored in our health system for research and planning purposes.

Linkage of health administrative datasets to CP registers has been trialled in other countries to inform delivery of healthcare services,[3] monitor the outcomes of orthopaedic strategies to prevent complications such as hip dislocation,[4] and to characterise hospital admissions in children with CP.[3] The unique clinical information regarding the severity of CP collected by CP-specific registers has facilitated an understanding of the healthcare needs of this patient population[5] and increased use of secondary care services[6] through linkage of CP registers with routinely collected health datasets. The Gross Motor Function Classification System (GMFCS)[7] is widely used to classify the functional ability of a child with CP. This is an ordinal scale of I–V, with children functioning at level V being the most severely affected by CP. The GMFCS predicts the need for surgery, in that children with GMFCS III–V are at higher risk of hip

displacement[4,8,9] and spinal deformity,[10,11] as well as the likely success rate of orthopaedic surgical procedures in these children. The GMFCS is used by clinicians assessing children with CP and their scores are routinely entered into the New Zealand Cerebral Palsy Register (NZCPR). The GMFCS score could be matched against the procedure code through data linkage, enabling analysis of procedures performed for CP according to severity.

To perform data linkage using our hospital dataset, we needed to verify the accuracy of the coding in the National Minimum Dataset. Specifically, we wanted to know whether these codes alone, without review of the clinical notes, could be linked with the data in the NZCPR to provide clinically useful demographic and clinical information.

The aims of this study were to (i) determine the accuracy of procedure codes for orthopaedic surgical procedures received by children with CP (ICD-10-AM/ACHI/ACS), (ii) use data linkage with the NZCPR to describe the demographic and clinical characteristics of children with CP who access orthopaedic surgical services at Starship Children's Hospital, and iii) determine if trends in the clinical and demographic data are useful for future service planning for children with CP.

Methods

Study setting

Starship Children's Hospital provides paediatric surgical services for all children living in the Auckland and Waitematā district health boards catchment areas and tertiary level surgical care for patients nationwide when necessary. Therefore, the total catchment area represents about 250,000 children aged 0–19 years.[12] Data for all children with an ICD-10-AM diagnostic code for CP (G80.9) who underwent surgical intervention in the Orthopaedics Department at Starship Children's Hospital between July 2013 and July 2018, and were aged 0–18 years at the time of their first procedure were extracted from the Auckland District Health Board (ADHB) database by a business intelligence data analyst. These data, including procedure codes, are sent to the Ministry of Health for inclusion in the National Minimum Dataset. Data for children over the age of 18 years at the time of the index surgery were excluded.

Data sources

Since 1993, the New Zealand Ministry of Health has routinely collected all public and private hospital inpatient and day-stay discharge information, including clinical and procedural details, in the form of the National Minimum Dataset (also known as Hospital Events data).[13] Each district health board is required to code and report this information to the Ministry of Health at monthly intervals. The National Health Index (NHI) number is a unique electronic identifier for each patient in New Zealand. Primary and secondary diagnoses at the time of discharge are coded using the International Statistical Classification of Diseases (ICD). CP (inclusive of all subtypes) is classified using ICD-10 diagnostic code G80.9. ICD 10th Revision Australian Modification (ICD-10-AM/ACHI/ACS) codes for all inpatient procedures, including surgeries, are checked against each event using the NHI number.

The NZCPR is a national register that was established in 2015. It collects health information relevant to CP (including demographic data, birth history, and clinical information such as type, topography, and severity). The NZCPR has estimated that there are approximately 2,490 individuals aged 0–19 years with CP in New Zealand.[14,15] A recent audit completed by the NZCPR at the request of the Health and Disability Ethics Committee found that coding for CP had a 99% accuracy rate for all ADHB hospital discharges from 2007 to 2017.[16]

Clinical records were accessed electronically through the ADHB portal. Study participants were identified by their NHI number only, and their clinical information was extracted and stored for review.

Coding accuracy

The raw data extracted by the analyst were processed initially using Microsoft Excel (Redmond, WA, USA) to extract variables of interest. The ICD-10-AM/ACHI/ACS codes for surgery/intervention were reviewed against the operation notes held within the electronic health records using the NHI. The surgical procedures were divided into five mutually exclusive categories (spine surgery, upper limb surgery, lower limb surgery, Botulinum (BTX)-A injection alone and "other") based on the coding information. The accuracy with which the ICD-10-AM/ACHI/ACS codes could be used to determine the procedures when matched against the operation notes in the medical records was assessed by two of the authors (WH, NW). If in-hospital events were recorded using more than one procedure code, the codes recorded were reviewed to determine the main procedure performed. The decision was made based on

whether the codes gave sufficient information to identify the surgical procedure when used alone.

Data linkage

We used the NHI number to bring together information from different parts of the National Minimum Dataset. The ICD10-AM G80.9 (International Classification of Diseases diagnosis code for Cerebral Palsy) and ICD-10-AM/ACHI/ACS (International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification [ICD-10-AM], the Australian Classification of Health Interventions [ACHI], and Australian Coding Standards [ACS]) are the coding systems used in New Zealand hospitals. These systems were developed by the World Health Organization and modified with permission for funding, service planning, research and audit purposes by the Australian Government. Data for sex, ethnicity, and GMFCS level were extracted from the NZCPR and linked to intervention codes using the NHI.

Data analysis

The intervention codes were interpreted to obtain further information about the anatomical site and type of procedure/surgery performed and supplemented with information from the clinical notes. Descriptive statistics for the type of surgical intervention and patient demographics were generated from the available data. Some children identified as ADHB admissions were not included in the NZCPR. Therefore, no demographic information could be extracted for these children.

Ethics approval

The ADHB Research Office approved this research as part of a service specific audit. Collection of health information for children and adults with CP from the NZCPR was approved by the Health and Disability Ethics Committee (approval number: 13/NTA/130). Individuals with CP who agree to their demographic and clinical information being collected and stored by the NZCPR also consent to their data being available for research purposes. Furthermore, after linkage, only de-identified data were available for analysis. Therefore, the requirement for informed consent was waived.

Results

Clinical information (in the form of clinical records and procedure code data extracted for hospital admissions) was available for 271 children. After exclusion of two patients whose medical notes did not include a diagnosis of CP and eight who were older than 18 years at the time of the index surgery, data for 261 children were included in the analysis. Two children reached the age of 18 years during the study period and were included in the study despite being older than the upper limit of age at the time of subsequent surgeries.

During the five-year study period, 261 children with a diagnosis of CP underwent 772 surgical procedures. The mean age at the time of the procedure was 8.46 years (range 1–22). Each child underwent a median of two procedures (range 1–10), and each procedure required an admission.

When determining the types of procedures performed and the accuracy of the ICD-10-AM/ACHI/ACS codes for categorising each procedure into one of the five broad types, we found that the codes had high accuracy for spine surgery (100%), BTX-A injection (100%), lower limb surgery (91%), and "other" types of surgery (95%). However, their accuracy for upper limb procedures was lower at 45%.

Following data linkage to the NZCPR, clinical and demographic information could be extracted for 232 (88.9%) of the 261 children. Table 1 summarises the patient demographics according to type of intervention received. Each hospital event and subsequent procedures were grouped into one primary type of surgery. Figure 1 shows the GMFCS level according to type of intervention performed. The GMFCS level was I–II in 57% of the 232 children, III in 11%, and IV–V in 32%.

Discussion

This study describes the orthopaedic surgical procedures performed for children with CP over a five-year period at the Starship Children's Hospital, a tertiary healthcare referral hospital in Auckland. In most cases, the ICD-10-AM/ACHI/ACS procedure code predicted the broad category of CP-related surgical intervention (upper limb, lower limb, spine, BTX-A, or "other"). Linkage of these data with the NZCPR identified the demographic and clinical characteristics of these children. The distribution of GMFCS levels in our study population (57% for grades I–II, 11% for grade III, and 32% for grades IV–V) is similar to that in the Australian Cerebral Palsy Report for 2018 (62%, 12%, and 26%, respectively).[17]

Data for specific surgical case numbers by clinical characteristics would help with service planning, including theatre space, perioperative care, and rehabilitation needs. For example, five

to six children with CP had spinal surgery each year during the five-year study period. Each case would typically require a bed in the paediatric intensive care unit and be the only patient on a whole day operating list. At the other end of the spectrum, approximately 100 children per year received BTX-A injections, with most requiring physiotherapy post-procedure. Demographic data could help with prediction of the perioperative care needs of these children. For example, the rehabilitation needs of a 3-year-old are different from those of an 18-year-old. Similarly, ethnicity data could help care providers to factor in the potential need for ancillary services, such as interpreters for some children and their families.

Similar to previous analyses of the characteristics of children with CP requiring hospital admission,[3,5,6] we found that linkage of procedural coding data with the demographic and clinical information in the NZCPR was helpful for descriptive analysis of children with CP requiring hospital level care. Building on local knowledge from similar methods used previously, we have validated the use of data linkage in New Zealand by linking data from the NZCPR with those in the National Minimum Dataset. For this project, we focused on the types of orthopaedic services required by children with CP according to their clinical and demographic characteristics, drawing on previous research that focussed on admissions data[3,5,6] to look more specifically at the surgical needs of children with CP.

Grouping of surgical interventions based on procedure codes allowed a broad understanding of the accuracy of our coding system. Prediction of surgical intervention was most accurate for spinal surgery and BTX-A injections. One difficulty with BTX-A injection is that it has only one code, so it is unknown if the procedure involved an upper or lower limb or which muscles were injected without reference to the clinical notes. The least accurate predictive ability was for upper limb surgery, which may reflect the typically generic codes used for upper limb procedures (e.g., "4796300, Open tenotomy, not elsewhere classified" and "4795700, lengthening of tendon, not elsewhere classified"). Therefore, without looking at the clinical records, it was impossible to determine if this procedure was for the upper or lower limb. Moreover, we noted instances of multiple codes, and at times duplicate codes, being used to describe the same procedure. For example, the ACHI code, "4842701 Osteotomy of proximal femur with internal fixation" was sometimes used for both varus de-rotation osteotomy and de-rotation osteotomy of femur. Therefore, the effectiveness and efficiency of this process may be limited when using ICD-10-AM/ACHI/ACS procedure codes alone as the sole source of information for data linkage.

The New Zealand Coding Authority at the Ministry of Health has quality assurance processes in place for resolving coding issues to ensure that the data entered into the National Minimum Dataset are collected accurately and consistently.[18] However, we encountered difficulties when using only the information from the procedure codes to inform the type of operation received. This could reflect both a limitation of the codes available that can be used in combination to accurately reflect the procedure and the process of selecting codes used immediately following a procedure in the operating room. Motivation to use the correct code or a combination of codes may be low among surgeons working in the public health system if these codes are not seen as valuable for monitoring clinical outcomes or needed for billing purposes (as in the private sector). However, with the increasing focus on quality and improvement of patient outcomes in the public health system, correct coding by clinicians is likely to become a focus of attention. The limitations in coding and data accuracy identified in this research were also noted in other data linkage studies.[3,5] Therefore, there is a need for better protocols for entering data into healthcare databases and more accurate coding of hospital data in the future. However, it should be borne in mind that although the accuracy of codes for surgical procedures has implications for research and audit activities, it is unlikely to affect resource utilisation in clinical practice. For example, a varus versus a de-rotation osteotomy of the femur will likely have a similar resource footprint.

In this study, we were able to link 88.9% of surgical procedures performed at Starship Children's Hospital over a five-year period to demographic and clinical data held by the NZCPR. Out of the 261 children included in the study, we could obtain information regarding the sex, ethnicity and GMFCS levels for 232 of them following data linkage. The demographic information was not extracted in the original dataset by the ADHB analyst.

The NZCPR is a relatively new register and presently has better data ascertainment for younger children with CP. Furthermore, since its introduction in 2004,[19] the GMFCS level has become easier to obtain in younger patients and

Table 1: Demographic and clinical data for paediatric patients with cerebral palsy obtained by linkage with the New Zealand Cerebral Palsy Register according to type of surgical intervention.

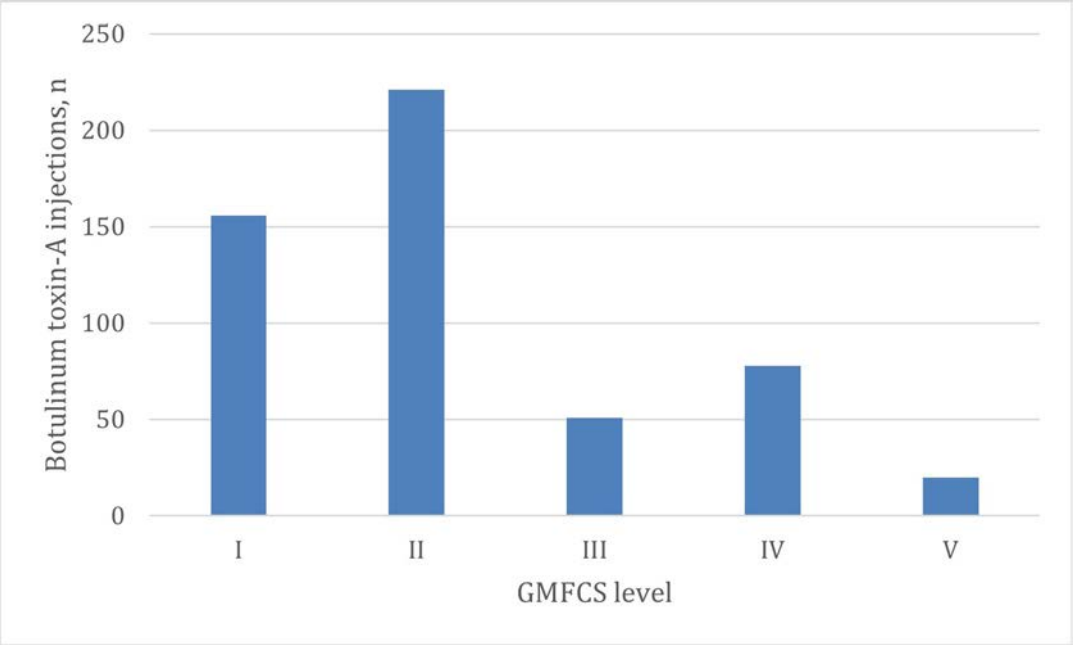
	Spinal surgery	**BTX-A only**	**Lower limb surgery**								**Upper limb surgery**		
	n=28*	**n=549****	**Single-event multilevel surgery, n=9*****	**Surgery for hip subluxation** **Soft tissue and bony surgery, n=33********	**Surgery for hip subluxation** **Metalware removal, n=23*****	**Foot surgery ± BTX-A, n=32[+]**	**Isolated calf operation, n=16[++]**	**Cast change/ removal of metal ware, n=18********	**Other, n=16[+]**	**Derotation of femur, n=4**	**Fusion ± BTX-A, n=4**	**Soft tissue ± BTX-A, n=38[+++]**	**Other, n=2*****
Mean age, years (SD)	12.83 (2.73)	7.43 (3.75)	10.89 (4.04)	8.09 (4.54)	9.04 (4.47)	12.06 (2.85)	11.38 (3.40)	11.17 (4.36)	12.6 (4.54)	11.25 (1.71)	15.25 (1.70)	11.5 (3.78)	12 (4.24)
Age range, years	6–19	1–19	5–16	2–16	2–17	6–18	4–16	3–16	3–22	9–13	13–17	2–19	9–15
Sex, M:F	9:13	320:212	5:3	19:11	14:8	12:15	9:3	8:7	6:5	2:2	4:0	14:22	1:0
GMFCS I	0	156	0	0	0	6	6	3	1	0	0	12	0
GMFCS II	0	221	4	1	8	6	4	7	2	4	1	12	1
GMFCS III	0	51	3	6	4	10	1	3	2	0	0	1	0
GMFCS IV	8	78	0	14	7	3	0	1	3	0	1	10	0

Table 1 (continued): Demographic and clinical data for paediatric patients with cerebral palsy obtained by linkage with the New Zealand Cerebral Palsy Register according to type of surgical intervention.

	Spinal surgery	**BTX-A only**	**Lower limb surgery**								**Upper limb surgery**		
	n=28*	**n=549****	**Single-event multilevel surgery, n=9*****	**Surgery for hip subluxation** **Soft tissue and bony surgery, n=33********	**Surgery for hip subluxation** **Metalware removal, n=23*****	**Foot surgery ± BTX-A, n=32⁺**	**Isolated calf operation, n=16⁺⁺**	**Cast change/ removal of metal ware, n=18********	**Other, n=16⁺**	**Derotation of femur, n=4**	**Fusion ± BTX-A, n=4**	**Soft tissue ± BTX-A, n=38⁺⁺⁺**	**Other, n=2*****
GMFCS V	14	21	0	9	3	2	0	1	3	0	1	1	0
Ethnicity, NZ European: Māori: PP: Other	13:4:4:1	367:50:41:74	7:0:0:1	14:11:4:1	13:7:2:0	21:2:2:2	8:1:1:2	10:2:2:1	7:2:1:2	4:0:0:0	2:0:2:0	23:8:1:4	0:1:0:0

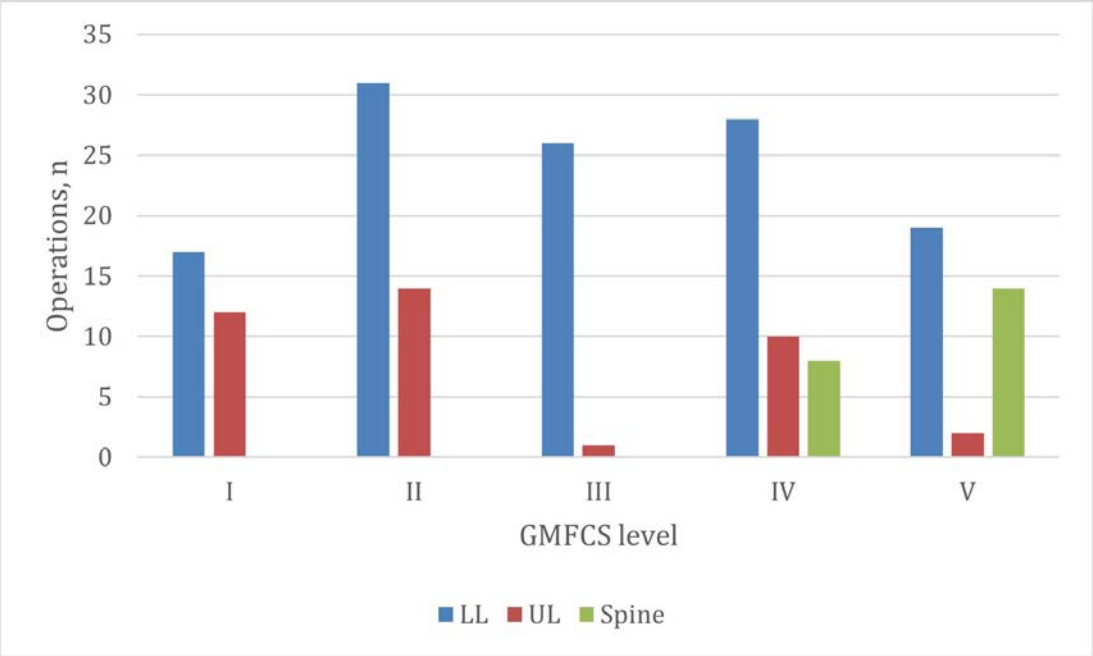
*No data linkage possible for 6 children.
**No data linkage possible for 17 children.
***No data linkage possible for 1 child.
****No data linkage possible for 3 children.
⁺No data linkage possible for 5 children.
⁺⁺No data linkage possible for 4 children.
⁺⁺⁺No data linkage possible for 2 children.
Other, all other ethnicities. BTX-A, Botulinum toxin-A;
GMFCS, Gross Motor Function Classification System;
PP, Pacific Peoples;
SD, standard deviation.

Figure 1a: Number of botulinum toxin-A injections administered according to GMFCS level.



GMFCS, Gross Motor Function Classification System.

Figure 1b: Number of surgical interventions according to GMFCS level.



GMFCS, Gross Motor Function Classification System; LL, lower limb surgery; UL, upper limb surgery.

its use has been slowly increasing in clinical practice.[20,21] An ability to compare the GMFCS levels and surgical needs of patients with CP would help to show trends in their utilisation of healthcare resources and predict future service demands. We hope that complete data linkage will be possible when the NZCPR becomes more established and GMFCS levels are more readily available.

An audit reported in 2003 found that the diagnostic coding used for the National Minimum Dataset required some form of change in 22% of cases and a change in the principal diagnosis in 11%.[22] Since then, coding practices have improved to the point that the data recorded are now accurate enough to be used for research purposes.[23] However, our study covered a period of five years, and there may have been some variations in both diagnostic and procedural coding practices over this time. These inconsistencies would be a limitation to using these codes alone for interpretation of procedures performed.

Whilst this study was designed to investigate the use of data linkage, it also identified potential ethnic disparity in the utilisation of orthopaedic surgical interventions. Under the principles of Te Tiriti o Waitangi, Māori have the right to input regarding decisions about the planning, development, and delivery of their healthcare services, to receive at least the same level of healthcare as non-Māori, and to have Māori cultural concepts safeguarded.[24] Further work aimed specifically at identifying inequities in service provision is needed to identify potential sources of systemic bias. The Royal Australasian College of Physicians regards the inequitable health outcomes experienced by Indigenous children as unacceptable and affirms that it is committed to taking action to eliminate those inequities at the individual, community and service levels.[25]

In conclusion, the findings of this study show that data linkage could help to inform the orthopaedic surgical needs and demographic and clinical characteristics of children with CP managed at Starship Children's Hospital. Data linkage could also be used at the national level to identify regional differences and assist with surgical planning. Furthermore, potential inequities in the health system have been identified. Ongoing partnership with Māori Health researchers and the NZCPR is needed to advocate for elimination of inequities in health care in children living with CP in Aotearoa New Zealand.

Accessibility of protocol, raw data and data linkage information

The raw NZCPR data analysed in this study can be made available by the NZCPR upon request.

COMPETING INTERESTS
Nil.

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Children's perspectives on the wicked problem of child poverty in Aotearoa New Zealand: a wearable camera study

Ryan Gage, Tim Chambers, Moira Smith, Christina McKerchar, Viliami Puloka, Amber Pearson, Ichiro Kawachi, Louise Signal

ABSTRACT

AIM: Child poverty is a wicked problem and a key determinant of health, but research on child poverty has relied largely on self-report methods and reports from parents or caregivers. In this study we aimed to assess aspects of child poverty using data collected by children using wearable cameras.

METHOD: The Kids'Cam Project recruited 168 randomly selected children aged 11–13 from 16 randomly selected schools in the Wellington Region of Aotearoa New Zealand. Each child wore a wearable camera for four consecutive days, recording an image every seven seconds. We used negative binomial regression models to compare measures of household resources, harms, behaviours and built environment characteristics between children living in low socio-economic deprivation households (n=52) and children living in high socio-economic deprivation households (n=26).

RESULTS: Compared with children living in conditions of low socio-economic deprivation, children living in conditions of high socio-economic deprivation captured significantly fewer types of fruit (RR=0.46), vegetables (RR=0.25), educational materials (RR= 0.49) and physical activity equipment (RR = 0.66) on camera. However, they lived in homes with more structural deficiencies (RR = 4.50) and mould (no mould was observed in low socio-economic deprivation households). They were also less likely to live in households with fixed heating (RR=0.27) and home computers (RR=0.45), and more likely to consume non-core food outside home (RR-=1.94).

CONCLUSIONS: The children in this study show that children in poverty face disadvantages across many aspects of their lives. Comprehensive policies are urgently needed to address the complex problem of child poverty.

Poverty adversely impacts on the realisation of children's rights to health and development. These rights are enshrined in international law in the United Nations Convention on Rights of the Child.[1] In developed countries, poverty can mean reduced access to nutritious food, lack of quality clothing such as warm clothes and sturdy shoes and reduced ability to see a doctor when needed.[2] Compared with their wealthier peers, children living in poverty are more likely to have poorer cognitive outcomes and school performance and are at an increased risk of antisocial behaviour and mental disorders.[3] These disadvantages cause flow-on effects such as poorer health and reduced employment prospects, resulting in broader social and economic costs due to expenditure on welfare, healthcare and criminal justice.

Poverty is a significant health and equity issue in Aotearoa New Zealand. Like many developed countries, poverty rates in Aotearoa New Zealand have been defined as the percentage of households that have disposable income less than 50% of the national median after housing costs.[4] Using this measure, 235,400 Aotearoa New Zealand children (20.8%) lived in poverty in 2018/19.[4] While Aotearoa New Zealand child poverty rates have gradually decreased since 2014/15,[4] child rates remain consistently higher than most other age groups and are almost twice the rate experienced in the 1980s.[5] Poverty in Aotearoa New Zealand is also ethnically patterned with Māori (the Indigenous population of Aotearoa New Zealand) and Pacific (mostly second generation migrants from Pacific Islands) children experiencing rates almost twice as high as NZ European children.[4] This consistent—and inequitable—burden of child poverty has been attributed to several social and economic factors, including the dominance of neoliberal (free trade) economics since the 1980s and a tendency for poverty to be framed as a minority ethnic issue.[5] The result is an environment that fails to support many children's right to healthy development and breaches principles of Te Tiriti o Waitangi, Aotearoa New Zealand's founding document, most notably the promotion of best health outcomes for Māori[6] and the United Nations Declaration on the Rights of Indigenous Peoples.[7]

Given the many consequences of child poverty, multidimensional research is important for documenting its effects.[2] Accounts of child poverty are largely based on self-report, report by adult caregivers, or household income surveys that typically only track the prevalence of child poverty. Often these accounts do not highlight children's poverty from the child's perspective. Moreover, the plight of children living in poverty is often difficult to convey to politicians and the wider population, as abstract numbers and references to disease and disadvantage do not translate easily into the consciousness of people for whom poverty is not a reality.

A new methodology developed by this research team, Kids'Cam, uses wearable cameras and Global Positioning Systems (GPS) to provide an objective and easily communicable account of children's lived experiences.[8,9] Using this data set, we aimed to assess aspects of child poverty, including children's access to household resources, household harms, their behaviours, and the nature of their built environments.

Methods

The Kids'Cam study

Kids'Cam was a cross-sectional observational study conducted in 2014/15. Full details on Kids'Cam's methodology, including the recruitment strategy and sample, are available elsewhere.[8,9] In brief, 168 randomly selected children aged 11–13 years were recruited from 16 randomly selected schools in the Wellington Region of Aotearoa New Zealand. Recruitment was stratified by ethnicity and school decile based on aggregate school enrolment data from the Ministry of Education to enable equal explanatory power for ethnicity (Māori, Pacific and NZ European) and socio-economic deprivation subgroups.[9] Each child wore a wearable camera and GPS recorder around their neck for four consecutive days, recording an image every seven seconds and GPS location every five seconds. Children were asked to wear the devices for all waking hours, and to remove the camera in situations where privacy could be expected, if they felt uncomfortable, when swimming or playing vigorous sport, or if requested.[9] Ethical approval was obtained to study all aspects of children's lives relevant to public health.[8]

Study sample

To compare the lived reality of child poverty, we selected a sub-sample of 78 Kids'Cam participants (46.4% of the original sample) from the lowest and highest levels of household socio-economic deprivation (NZiDep quintiles 1 and 5, respectively). NZiDep is based on eight questions relating to material and social deprivation,[10] categorised as: 1—zero deprivation characteristics (least deprived); 2—one deprivation characteristic; two deprivation characteristics; 4—three or four deprivation characteristics; and 5—five or more deprivation characteristics (most deprived). There were more participants in the low socio-economic deprivation group (n=52) than the high socio-economic deprivation group (n=26), which reflects national trends for socio-economic deprivation.[2] There were similar age and gender distributions between groups, but fewer NZ European participants in the high deprivation group (Table 1).

Measures

We coded for a range of household resources, household harms, behaviours and built environment characteristics (see Appendix 1), using images captured on Thursday and Saturday during children's leisure time. We defined leisure time as "all hours outside school time", which includes Thursday morning before school, Thursday afternoon after school and Saturday. All data were recorded in a pre-formatted Excel spreadsheet in 2019.

Household resources included fruit, vegetables, educational materials, cognitive stimulation materials, "personal items" such as cell phones and games, physical activity equipment and play spaces, and the presence of computers, heating and fixed heating. We also coded for children's sleeping arrangement (own room vs shared room). Household harms included structural deficiencies and mould in participants' homes and the presence of alcohol. Behaviours included children's consumption of "core" and "non-core" foods (defined using a nutrient profiling model)[11] and children's participation in educational activities, structured physical activity and unstructured physical activity. Built environment characteristics included physical disorder in children's neighbourhoods (defined as the area 500m—as the crow flies—from their residential address, based on children's GPS data that is detailed elsewhere).[12] We coded for three types of disorder: fixed (vacant or dilapidated buildings); semi-fixed (graffiti and dilapidated lots with more easily fixed elements); and moveable (litter and abandoned items), based on definitions in a previous study.[13]

Statistical analysis

We used Stata/IC 15 for all statistical analyses. To compare differences by household socio-economic deprivation, we used negative binomial

regression models to estimate mean rates and rate ratios for each poverty variable, using low socio-economic deprivation children as the reference group for all comparisons. For count-based variables, rates represent the mean number of unique items of each variable per household. Count-based variables include fruit, vegetables, educational materials, cognitive stimulation, structural deficiencies, physical activity equipment, play spaces and "personal items". Our analysis of these variables represents "variety" in a household, as each item type was only counted once. For binary variables, rates represent the proportion of children's households that had the variable present. Binary variables include alcohol presence, computer access, heating, fixed heating and "own room for sleeping". For behaviours (food consumption and children's participation in educational activities, structured physical activity and unstructured physical activity), rates represent the mean frequency of each behaviour divided by recording time (rescaled as a mean rate per hour). Likewise, mean rates for neighbourhood physical disorder represent participant's frequency of exposure to disorder divided by the recording time in outdoor settings, rescaled as a mean rate per hour spent outdoors. We also explored the association between children's exposure to physical disorder and neighbourhood-level deprivation (NZiDep), using low deprivation neighbourhoods as the reference group. Differences in poverty variables by ethnicity are described, but further analysis was not undertaken due to low numbers. All analyses accounted for the differential probability of selection into the study, using Stata's svy commands and associated sampling weights.

Results

Children in this study captured a mean of 2,482 images during leisure time in the two-day recording period, equivalent to a mean of 4.8 hours, including 3.0 hours in homes and 1.8 hours in other settings (Table 1). Low socio-economic deprivation children captured more images inside their homes compared to high socio-economic deprivation children (Table 1). However, this difference was driven by several outliers in the low socio-economic deprivation group who captured substantial data in these settings. There was no difference in median photos captured between deprivation groups (nonparametric equality of medians test: p=0.230).

Household resources and harms

Children living in conditions of high socio-economic deprivation captured fewer types of fruit (RR=0.46, 95%CI 0.25–0.85), vegetables (RR=0.25, 95%CI 0.14–0.58), educational materials (RR=0.49, 95%CI 0.37–0.65), physical activity equipment (RR=0.66, 95%CI 0.45–0.96) and 'personal interest' items (RR=0.66, 95%CI 0.48, 0.90) on camera than children living in conditions of low socio-economic deprivation (Table 2). Fruit and vegetables were observed stored in fridges, pantries, freezers and counter tops, and during food consumption. In low socio-economic deprivation households, fruit was more often positioned in locations visible to children, e.g., in "fruit bowls" on spacious countertops (Figure 1). More structural deficiencies (RR=4.50, 95%CI 2.48–8.15) and mould were observed in high socio-economic deprivation households compared to low socio-economic deprivation households (no mould was observed in low socio-economic deprivation households) (Figure 1). Children living in conditions of high socio-economic deprivation were less likely to have computer access (RR=0.45, 95%CI 0.25–0.80), less likely to sleep in their own room (RR=0.50, 95%CI 0.28–0.91) and less likely to have a fixed source of heating (RR=0.27, 95%CI 0.10–0.71). Alcohol presence was not associated with socio-economic deprivation. Children living in conditions of low socio-economic deprivation usually had their own "personal space", including their own bedroom, a desk for studying and collections of "personal items" such as books, posters and games (Figure 1). In contrast, children living in conditions of high deprivation children had less defined "personal spaces" and less material possessions.

Child behaviours

Socio-economic deprivation was not associated with the total amount of food items consumed. However, children living in conditions of high socio-economic deprivation consumed more non-core food items (RR=1.39, 95%CI 1.03–1.98), including nearly twice as many non-core food items outside home (RR=1.94, 95%CI 1.18–3.20). This was due to increased consumption of sweets, ice creams and snack foods purchased from convenience stores and fast food outlets. They also consumed fewer core items outside home than children living in conditions of low socio-economic deprivation (RR=0.13, 95%CI 0.03–0.58).

Children living in conditions of high socio-economic deprivation appeared to participate in fewer educational activities and structured physical activities than children living in condi-

tions of low socio-economic deprivation, but the results were not significant at the 95% confidence level. Socio-economic deprivation had little influence on children's participation rate in unstructured physical activities. Backyards were popular spaces for unstructured physical activity, for both children living in high and low socio-economic deprivation (Figure 1).

Built environment characteristics

For each hour children spent outdoors in their neighbourhood, they were exposed to a mean of 0.9 fixed physical disorder items (mostly private dilapidated properties), 12.1 semi-fixed physical disorder items (mostly graffiti) and 6.1 moveable physical disorder items (mostly waste). Household socio-economic deprivation was not associated with children's exposure to fixed, semi-fixed and moveable physical disorder. Children from high deprivation neighbourhoods were exposed to more disorder (4.5 times more fixed items, 1.5 times more semi-fixed items and 3.3 times more moveable items than children from low deprivation neighbourhoods), but these results were insignificant at the 95% confidence level.

Differences by ethnicity

Māori children captured fewer types of fruit (RR=0.59, 95%CI 0.37, 0.95), educational materials (RR=0.56, 95%CI 0.46, 0.68), cognitive stimulation materials (RR=0.41, 95%CI 0.24, 0.69), "personal items" (RR=0.76, 95%CI 0.24, 0.69) and physical activity equipment (RR=0.49, 95%CI 0.29, 0.84) on camera than NZ European children. Likewise, Pacific children captured fewer types of fruit (RR=0.44, 95%CI 0.24, 0.80), educational materials (RR=0.55, 95%CI 0.39, 0.78), cognitive stimulation materials (RR=0.27, 95% CI 0.16, 0.44), "personal interest" items (RR=0.64, 95% CI 0.48, 0.86) and physical activity equipment (RR=0.52, 95%CI 0.32, 0.84) than NZ European children, and were less likely than NZ European children to have a fixed source of heating (RR=0.67, 95%CI 0.49, 0.91).

Table 1: Sample characteristics.

Characteristic	Total sample	Low socio-economic deprivation group	High socio-economic deprivation group
n	**78 (100)**	**52 (66.7)**	**26 (33.3)**
Gender, n (%)			
Female	36 (50.0)	21 (43.8)	15 (62.5)
Male	36 (50.0)	27 (56.2)	9 (37.5)
Ethnicity, n (%)			
NZ European	33 (45.8)	28 (58.3)	5 (20.8)
Māori	25 (34.7)	13 (27.1)	12 (50.0)
Pacific	14 (19.5)	7 (14.6)	7 (29.2)
Images captured, mean (95%CI)			
Total	2,550 (2,172; 2,928)	2,840 (2,356; 3,324)	1,944 (1,429; 2,459)
Home settings	1,601 (1,295; 1,908)	1,849 (1,448; 2,250)	1,086 (715; 1,456)
Non-home settings	9,48 (741; 1,155)	991 (713; 1,269)	858 (585; 1,131)
Observation hours, mean (95%CI)			
Total	5.0 (4.2; 5.7)	5.5 (4.6; 6.5)	3.8 (2.8; 4.8)
Home settings	3.1 (2.5; 3.7)	3.6 (2.8; 4.4)	2.1 (1.4; 2.8)
Non-home settings	1.8 (1.4; 2.2)	1.9 (1.4; 2.5)	1.7 (1.1; 2.2)
Image quality, % usable (95%CI)	96.6 (95.2; 97.8)	97.3 (96.0; 98.6)	95.0 (92.1; 97.8)

Table 2: Mean rate and rate ratios comparing household resources, household harms, behaviours and physical disorder exposures by household socio-economic deprivation.

Variable	Socio-economic deprivation group	Mean rate (95%CI)	Rate ratio (95%CI)
Types of household resources/harms [a]			
Fruit	Low (ref)	3.34 (2.82; 3.96)	1
	High	1.16 (0.85; 2.83)	0.46 (0.25; 0.85)*
Vegetables	Low (ref)	3.24 (2.17; 4.85)	1
	High	0.94 (0.49; 1.80)	0.29 (0.14; 0.58)*
Educational material	Low (ref)	5.51 (4.84; 6.19)	1
	High	2.69 (1.87; 3.52)	0.49 (0.37; 0.65)*
Other cognitive stimulation materials	Low (ref)	1.32 (0.92; 1.89)	1
	High	0.71 (0.30; 1.67)	0.54 (0.20; 1.48)
Physical activity equipment	Low (ref)	2.93 (2.39; 3.59)	1
	High	1.93 (1.24; 3.01)	0.66 (0.45; 0.96)*
Play spaces	Low (ref)	0.98 (0.75; 1.28)	1
	High	0.75 (0.58; 0.97)	0.76 (0.55; 1.06)
"Personal interest" items	Low (ref)	5.34 (4.29; 6.65)	1
	High	3.51 (2.79; 4.42)	0.66 (0.48; 0.90)*
Structural deficiencies	Low (ref)	0.69 (0.37; 1.29)	1
	High	3.12 (1.92; 5.09)	4.50 (2.48; 8.15)*
Mould	Low (ref)	0	-
	High	0.47	-
Presence of household resources/harms[b]			
Computer access	Low (ref)	0.97 (0.94; 1.01)	1
	High	0.43 (0.24; 0.77)	0.45 (0.25; 0.80)*
Heating	Low (ref)	0.82 (0.74; 0.90)	1
	High	0.71 (0.53; 0.96)	0.87 (0.65; 1.78)
Fixed heating	Low (ref)	0.75 (0.66; 0.85)	1
	High	0.20 (0.08; 0.50)	0.27 (0.10; 0.71)*
Own room for sleeping	Low (ref)	0.97 (0.94; 1.01)	1
	High	0.49 (0.26; 0.90)	0.50 (0.28; 0.91)*
Alcohol presence	Low (ref)	0.49 (0.36; 0.67)	1
	High	0.41 (0.21; 0.79)	0.84 (0.41; 1.73)

Table 2 (continued): Mean rate and rate ratios comparing household resources, household harms, behaviours and physical disorder exposures by household socio-economic deprivation.

Variable	Socio-economic deprivation group	Mean rate (95%CI)	Rate ratio (95%CI)
Children's behaviours[c]			
Total foods consumed	Low (ref)	1.35 (1.13; 1.61)	1
	High	1.40 (1.00; 1.96)	1.04 (0.68; 1.59)
Core foods consumed	Low (ref)	0.78 (0.59; 1.03)	1
	High	0.58 (0.38; 0.89)	0.75 (0.41; 1.38)
Non-core foods consumed	Low (ref)	0.58 (0.48; 0.70)	1
	High	0.81 (0.56; 1.17)	1.39 (1.03; 1.87)
Core foods consumed (home only)	Low (ref)	1.01 (0.73; 1.40)	1
	High	0.89 (0.59; 1.34)	0.88 (0.47; 1.63)
Non-core foods consumed (home only)	Low (ref)	0.51 (0.40; 0.66)	1
	High	0.49 (0.33; 0.73)	0.95 (0.61; 1.50)
Core foods consumed (outside home)	Low (ref)	0.38 (0.26; 0.57)	1
	High	0.05 (0.01; 0.22)	0.13 (0.03; 0.58)*
Non-core foods consumed (outside home)	Low (ref)	0.65 (0.50; 0.84)	1
	High	1.26 (0.65; 2.46)	1.94 (1.18; 3.20)*
Structured educational activities	Low (ref)	0.22 (0.12; 0.40)	1
	High	0.05 (0.01; 0.26)	0.25 (0.06; 1.12)
Structured physical activity	Low (ref)	0.06 (0.03; 0.13)	1
	High	0.01 (0.00; 0.03)	0.23 (0.04; 1.22)
Unstructured physical activities	Low (ref)	0.13 (0.07; 0.24)	1
	High	0.22 (0.07; 0.67)	1.14 (0.74; 2.54)
Children's exposure to neighbourhood disorder[d]			
Fixed disorder	Low (ref)	0.51 (0.19; 1.35)	1
	High	1.51 (0.58; 3.92)	2.97 (0.75; 11.81)
Semi-fixed disorder	Low (ref)	11.58 (6.69; 20.07)	1
	High	13.48 (5.43; 33.46)	1.16 (0.40; 3.35)
Moveable disorder	Low (ref)	6.98 (3.38; 13.62)	1
	High	4.28 (1.63; 11.25)	0.61 (0.19; 1.98)

*Statistical significance ($p<0.05$)

[a] Mean rate represents the unique number of items observed over the two-day observation period.

[b] Mean rate represents the proportion of households in which the variable was observed over the two-day observation period.

[c] Mean rate represents the behaviour frequency (e.g., food items eaten) divided by observation hours, rescaled to represent a mean rate per hour of observation time.

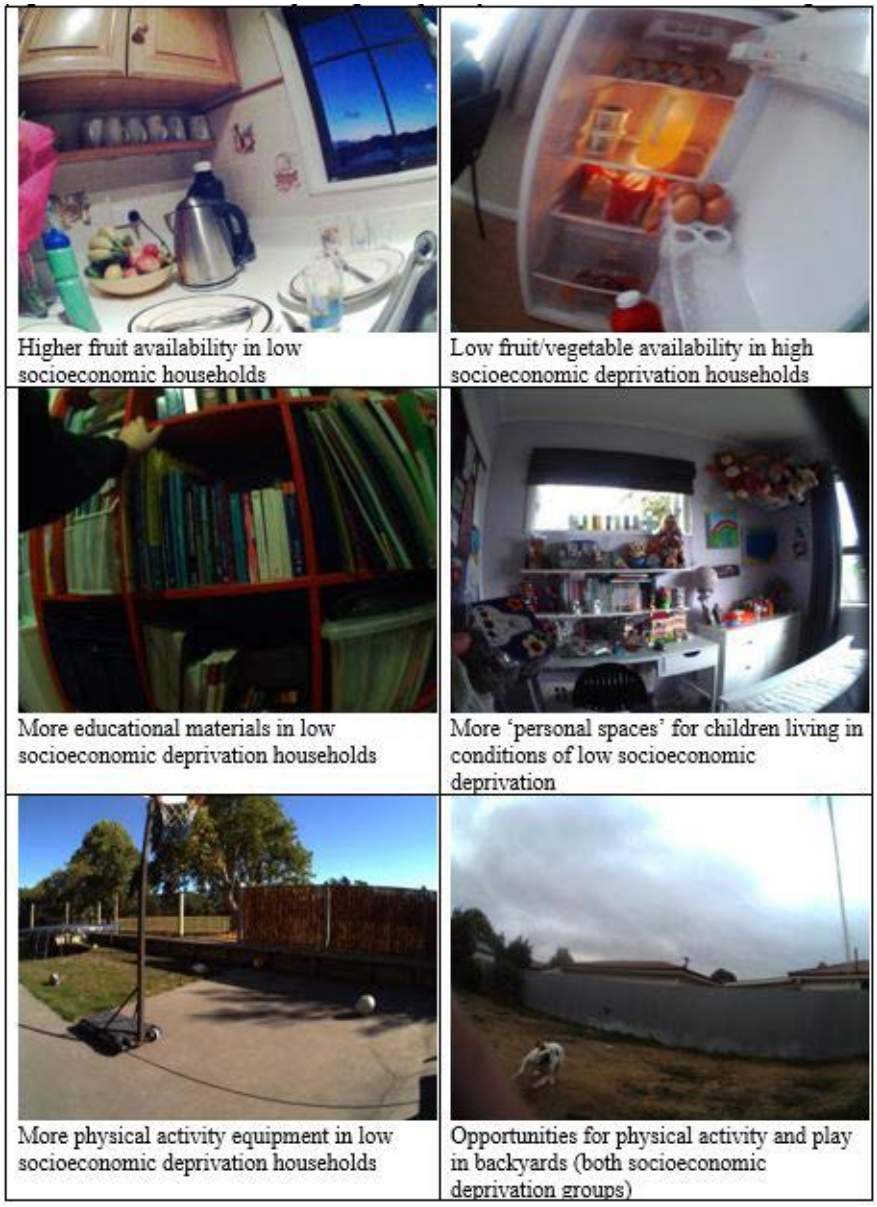
[d] Mean rate represents children's exposure to disorder items divided by observations hours outdoors, rescaled to represent a mean rate per hour observation time.

Discussion

The images in this study illustrate that children living in poverty face disadvantages across many aspects of their lives. Children living in conditions of high socio-economic deprivation lived in households with fewer types of fruit, vegetables, educational materials, physical activity equipment and "personal items", and more structural deficiencies and mould. They were also less likely to sleep in their own room and have access to a computer and fixed heating. These differences highlight a number of health concerns. Low availability of fruit and vegetables is associated with lower consumption of fruit and vegetables among children.[14] Fewer educational materials may present barriers for completing schoolwork and negatively affect school performance.[15] Moreover, poor housing conditions such as mould, structural deficiencies and lack of heating have several adverse implications for children's health, including increased hospitalisation rates and stress.[16,17]

While most variables assessed have clear links to health, the health implications of having fewer "personal items" such as smartphones and toys can be both positive and negative. On one hand, a lack of material possessions can negatively affect children's wellbeing[18] and reduce their capacity to pursue their own interests. On the other, excessive use of certain items, such as smartphones and videogames, can negatively affect the psychological health of some children.[19,20] Moreover, there is

Figure 1: Differences between privilege and poverty observed in wearable camera images.



rising concern over increasing commercialisation of children's environments,[21,22] which promotes materialism and may decrease life satisfaction among children.[23]

High deprivation children were more likely to consume non-core foods outside their home than low deprivation children. This could partly be explained by the obesogenic environment in which high deprivation children live.[24] Previous research shows that high socio-economic deprivation neighbourhoods in Aotearoa New Zealand have higher densities of unhealthy food outlets, such as convenience stores and fast food outlets.[25] Children in this study frequently purchased confectionery and sugary drinks from convenience stores, which may have particularly appealed to high deprivation children because of the typically low cost of these items.[26] Fast food may also appeal to low-income families because of its convenience and low cost compared with other eating out options.[27]

While insignificant at the 95% confidence level, it appeared that high socio-economic deprivation children were less likely to participate in structured physical activity. This is consistent with previous evidence[28–30] and is not surprising given the costs associated with participating in sport, e.g., training fees, and the purchasing of uniforms and equipment. In contrast, there was no association between socio-economic deprivation and unstructured physical activity. Backyards were popular spaces for unstructured physical activity among both socio-economic deprivation groups. This may reflect Aotearoa New Zealand's traditional residential design, which appears to benefit children equally in terms of opportunities for outdoor physical activity and play.

Due to a history of colonisation, and institutional racism, child poverty is ethnically patterned in Aotearoa New Zealand, with Māori and Pacific children bearing a disproportionate burden.[5] While this study was underpowered to undertake detailed subgroup analyses, we found that Māori and Pacific captured fewer types of fruit (Māori only) educational materials, cognitive stimulation, "personal items", physical activity equipment and fixed heating (Pacific only) in their homes than NZ European children.

This study has some limitations. First, we could not ascertain children's perceptions of the variables under study. Although each variable was relevant for health (Appendix), their importance for children could depend on several factors, including external support (e.g., from schools) and cultural values (e.g., materialism and collectivism).[31] Second, wearable cameras were not suited for studying some important aspects of poverty, including clothing (because participant's clothing was not usually visible) and overcrowding. Third, the method likely underestimated household resources that were stored out of sight, such as educational materials in drawers, food in cupboards and central heating. Finally, high deprivation children captured fewer images in home settings than low deprivation children, which may have resulted in an underestimation of their household resources. However, we do not believe this resulted in substantial bias, given that median recording time was similar between groups, children were highly mobile (thus enabling photo capture from different areas and vantages) and counts of household resources were not affected by the frequency with which they were captured (i.e., each resource type was only counted once).

Wearable cameras for poverty measurement: research implications

Wearable cameras have several advantages compared with population-based surveys of child poverty. The cameras enable poverty to be observed from the child's perspective as they wear the cameras throughout their day. Underestimation is common in surveys, owing to report bias and the fact that people are often unaware of the factors around them. In contrast, this study demonstrates that wearable cameras can be used to capture a wide range of variables relevant to poverty. Moreover, the methodology allows the capture of contextual information such as sources of junk food consumed and the relative advantage of "personal space" for children to pursue their own interests.

Wearable cameras offer advantages and disadvantages compared to alternative visual methodologies such as Photovoice. Photovoice provides participants with cameras to help identify issues of concern and holds discussions with them to reflect upon these issues.[32] Compared to Photovoice, wearable cameras offer a more comprehensive and "objective" approach in that a wide range of aspects of participants' lives can be studied. In this regard, it is analogous to passive momentary exposure assessment, such as wearable air pollution monitors used in environmental epidemiology.[33] In contrast, data from Photovoice is filtered through participants' choices. While less detailed, it enables participants to identify the most salient features of their lived experience. Wearable camera research could be

strengthened by use of qualitative interviews or group discussions, like Photovoice. Researchers should consider the use of wearable cameras to study child poverty from children's perspectives.

Conclusions

This study illustrates that children in poverty face disadvantages across many aspects of their lives in breach of their rights under international law.[1] This "accumulation" of disadvantage can adversely affect their health and development and interfere with their right to an adequate standard of living. In the Aotearoa New Zealand context, the disproportionate burden experienced by Māori children breaches Te Tiriti o Waitangi and the United Nations Declaration on the Rights of Indigenous Peoples.[7] Pacific children also carry a heavier burden, as is true internationally of Indigenous and minority populations. From a policy perspective, the children in this study highlight the urgent need for comprehensive policies to improve outcomes for children in poverty. Although targeted policies (e.g., school food programmes)[34] can improve some consequences of child poverty, multi-pronged approaches are needed to help ensure equal living standards and opportunities for all children.[2] This should include community development initiatives that empower communities to address the "wicked" problem of child poverty.[35] While based in Aotearoa New Zealand, this study has relevance for child poverty in similar jurisdictions, particularly those with Indigenous and minority communities.

COMPETING INTERESTS
Nil.

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Appendices

Appendix 1: Definitions for wearable camera analysis.

Factor	Definition	Health link
Nutrition		
Fruit	Count of exposures to fruit at home. Each type of fruit was only counted once. Food items with >1 fruit, e.g., fruit salad, counted as one type of fruit.	Consumption of a variety of fruit has health benefits.[1]
Vegetables	Count of exposures to vegetables at home. Each type of vegetable was only counted once. Items with >1 vegetable, e.g., mixed vegetables, counted as one type of vegetable. Excluded frozen chips.	Consumption of a variety of vegetables has health benefits.[1]
Alcohol availability	Presence of alcohol in the home. Included the contents of cups if there was evidence that it was filled with alcohol. Excludes marketing and empty bottles. Binary variable.	Home availability of alcohol increases youth alcohol use.[2]
Consumption of core and noncore food and beverages	Count of core and noncore foods and beverages consumed inside the child's home. Definitions of core and non-core products were sourced from a nutrient profiling model.[3]	Multiple health links, including energy intake, obesity, malnutrition, diabetes, heart disease and dental health.
Education		
Educational materials	Count of educational material, including fiction books, nonfiction books, stationary, exercise books/ other paper materials, arts and craft materials and educational posters. Each type of material was only counted once.	Sources of cognitive stimulation at home are associated with children's school performance.[4] Educational materials may be required for school work.
Home computer	Presence of a computer at home. Binary variable.	Sources of cognitive stimulation at home are associated with school performance.[4] A computer may be required for school work.
Cognitive stimulation	Count of other mentally stimulating items, such as music equipment, certain board games (e.g., scrabble), toys with a creative or constructive element (e.g., lego and model planes) and jigsaw puzzles. Each type of material was only counted once.	Sources of cognitive stimulation at home are associated with school performance.[4]

Appendix 1 (continued): definitions for wearable camera analysis.

Factor	Definition	Health link
'Personal items'	Count all other types of toys/entertainment/ hobby matterial, such televisions, games, movies, game consoles, posters in child's room, soft toys and non-stimulating toys (e.g., race cars). Each type of material was only counted once.	A lack of material possessions can negatively affect children's wellbeing.[5] However, excessive use of certain items such as smartphones and videogames can negatively affect the psychological health of some children.[6,7]
Structured educational activity	Count of structured learning activity with parents or other children, e.g., music and craft classes.	Cognitive stimulation, particularly through parent-child activities, is positively associated with school performance.[4]
Physical activity/ play		
Structured physical activity	Count of structured physical activities the participant took part in, such as netball, swimming and rugby.	Physical activity is associated with numerous physical, psychological and social health benefits in children.[8] Structured sport is especially beneficial due to the social nature of participation.[9]
Other physical activity or play	Count of non-structured of physical activity or play activities, such as walks with family, running, cycling and scootering. Excluded brief walks of less than 5m duration. Excluded walks to other destinations in which play or physical activity was not the main purpose, such trips to a convenience store. Excluded active transport to and from school on Thursday, which were tallied separately.	Physical activity is associated with numerous physical, psychological and social health benefits in children.[8]
Physical activity equipment at home	Count of physical activity equipment at home, such as balls, racquets and basketball hoops. Excluded sports clothing and sports bags. Each type of equipment was only counted once.	Physical activity rates among children can depend on physical activity equipment at home.[10]
Play space at home	Count of spaces that offer opportunities for play at home, such as backyards.	Physical activity rates among children can depend on physical activity equipment at home.[10]
Active transport on Thursday	Evidence that the participant used active transport to or from school on Thursday, such as walking, cycling, scootering or skateboarding. Binary variable.	Active transport can increase the time children spend in physical activity.[11]
Housing conditions		
Heating	The type(s) of heating observed in the participant's home. Included fixed heating e.g., heat pumps and fireplaces, and non-fixed heating e.g., oil heaters and fan heaters. Factor variable: 1) no heating 2) fixed heating 3) non-fixed heating.	Living in a cold homes is associated with poorer overall health and increased hospitalisation rates.[12]

Appendix 1 (continued): definitions for wearable camera analysis.

Factor	Definition	Health link
Child sleeping arrangement	The child's sleeping arrangement: shared room or own room.	Associated with overcrowding, which can impact children's health and wellbeing.[13]
Mould	Count of mould in the participant's home, both interior and exterior. Mould exposures on each surface (e.g., ceiling, wall) were only counted once.	Mould is associated with respiratory and allergic effects.[14]
Structural deficiencies	Count of structural deficiencies in the participant's home, such as physical damage on walls, doors, ceilings, external walls, broken windows, faulty windows, peeling paint and rot. Also included moss on driveways.[15]	Structural deficiencies may effect thermal efficiency or other functions, and may negatively children's wellbeing.[16]
Physical disorder		Physical disorder in a neighbourhood can affect children's stress markers, perceived safety and willingness to participate in physical activity.[17,18]
a) Fixed elements	Fixed elements are defined as those that are: "more permanent and requiring more resources and time to change, such as a vacant or dilapidated building."[19]	
Dilapidated buildings (fixed)	Count of exposures to buildings with "broken features," "peeled paint," or "boarded up windows."[19]	
Vacant buildings	Count of exposures to buildings that had "any visible signs that no one is inhabiting/leasing it."[19]	
b) Semi-fixed elements	Semi-fixed elements are defined as those that are: "Somewhat less permanent and easier to change, such as a dilapidated lot overgrown with weeds or broken but more easily fixed elements, such as a broken window."[19]	
Dilapidated buildings (semi-fixed)	Count of exposures to buildings with structural damage that is more easily fixable. Included properties with worn fences, e.g. worn/ faded paint, scattered litter in the yard, graffiti, and properties "with overgrown (knee high or higher) grass, weeds, shrubbery or scattered litter in the yard.[19]	
Unmaintained parks	Count of public parks with overgrown grass and playgrounds with worn/ damaged equipment.[19]	

Appendix 1 (continued): definitions for wearable camera analysis.

Factor	Definition	Health link
Graffiti	Count of exposures to graffiti. Included graffiti from spray paint, permanent marker and 'scratched' tags, e.g., from a knife or fingernail. Multiple sources of graffiti on one surface were only counted once.	
Ex-graffiti	Count of surfaces on which paint was used to hide graffiti.	
c) Moveable items	Moveable items are defined as "non-fixed features, such as litter."[19]	
Waste	Count of exposures to waste. Excluded waste in participant's home. Clusters of waste were only counted as one exposure.	
Abandoned items	Count of abandoned items, such as tyres, couches, washing machines.	
Broken glass	Count of exposures to broken glass.	

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Delay in funding of tolvaptan for polycystic kidney disease in Aotearoa New Zealand

Tracy Chan, Walter van der Merwe, Janak R de Zoysa

ABSTRACT

Autosomal dominant polycystic kidney disease (ADPKD) is the fifth most common cause of end stage kidney disease (ESKD) in Aotearoa New Zealand.[1] Identification of two genes, PCKD1 and PCKD2, which cause the majority of this disease, has played a key role in the development of DNA-sequence molecular diagnostics.[2,3] ADPKD is characterised by the formation and growth of multiple cysts within the kidney, with some but not all patients progressing to ESKD. The diagnosis of ADPKD is based on the presence of family history, and radiological imaging although increasingly genetic testing is being used for screening and diagnosis.[4]

Once diagnosed, standard management of ADPKD includes laboratory monitoring of chronic kidney disease (CKD) parameters, lowering of blood pressure, and a high fluid intake. Over the last decade much research has been undertaken for targeted therapies for ADPKD; however, despite funding of these medications overseas since May 2015, and applications to Te Pātaka Whaioranga, The Pharmaceutical Management Agency (PHARMAC), these therapies remain unavailable to New Zealanders resulting in an increased burden of disease to individuals and the whānau and financial cost to the health system.[5]

Autosomal dominant polycystic kidney disease (ADPKD) is characterised by the formation and growth of multiple cysts within the kidney that distort and destroy the kidney structure and function. Hypertension occurs ubiquitously as the disease progresses, and macroscopic haematuria, flank pain, rupture of cysts, cyst infection and kidney stones are all common. Some, but not all, patients will progress to end stage kidney disease (ESKD). Extra-renal disease can also occur with cysts in other organs, cerebral aneurysms, aortic root dilatation and cardiac valvular abnormalities.

The most common cause of inherited kidney disease

ADPKD is the fifth most common cause of ESKD (Figure 1) and accounts for 7.3% of patients on renal replacement therapy (dialysis and transplant) in Aotearoa New Zealand.[1] This figure is consistent with reports from overseas where ADPKD accounts for 5–10% of patient with ESKD.[6] The number of patients with polycystic kidney disease (PCKD) who do not start renal replacement therapy is uncertain. ADPKD affects all races; however, ethnic differences in incidence and outcome in Aotearoa New Zealand are uncertain. The prevalence is generally reported as 1:400–1:1000 from early landmark studies from Denmark[7] and the USA.[8]

PCKD1 and PCKD2 encode the integral membrane protein polycystin-1 and polycystin-2 respectively, which interact via signalling pathways in primary cilia, and account for the majority of cases.[9] Ten to fifteen percent of patients will have no mutation in these genes due to mutations in additional rare cystic disease genes or somatic mosaicism, the presence of two genetically distinct cell populations within one individual resulting from a somatic mutation during embryogenesis. Genetic testing is available in New Zealand and is usually ordered after discussion with the Genetics Health Service NZ.

Standard therapy of ADPKD

No direct randomised controlled trials have been undertaken in this area; however, general lifestyle interventions are recommended targeted at maintaining a healthy weight, avoiding dehydration, not smoking, and limiting dietary sodium to 100mmol/day and protein intake to 0.75–1gm/kg/day.[10,11]

Early detection and aggressive treatment of hypertension is vital. Use of agents to block the renin angiotensin system are safe and effective; however, individualised therapy based on co-morbidities and stage of chronic kidney disease is appropriate.[10]

Research in the last decade

Individuals with the PCKD1 gene tend to have a more severe phenotype, and make up the majority of ADPKD patients who progress to ESKD in middle age. Nevertheless, disease progression can vary considerably, even within families.[12] It is now well established that renal outcome in the individual patient, is a function of current kidney size (height-adjusted total kidney volume), kidney function, and age. The Mayo ADPKD calculator incorporates these parameters to predict renal outcomes over a period of 5–40 years.[13] Expensive and potentially hazardous therapies need to be targeted at those who are most likely to benefit from them, and the Mayo calculator is an effective tool for the clinician assessing possible benefit of new therapies in an ADPKD patient.

There has been very active research in pharmacological treatment of ADPKD with therapies including statins,[14,15] mTor inhibitors,[16,17] and somatostatin analogues.[18] Various agents are being trialled including: metformin, pioglitazone, tyrosine kinase inhibitors, oral glucosyl-ceramide synthase inhibitors, and non-peptide vasopressin 2 receptor antagonists.[19]

Tolvaptan, a new hope for PCKD

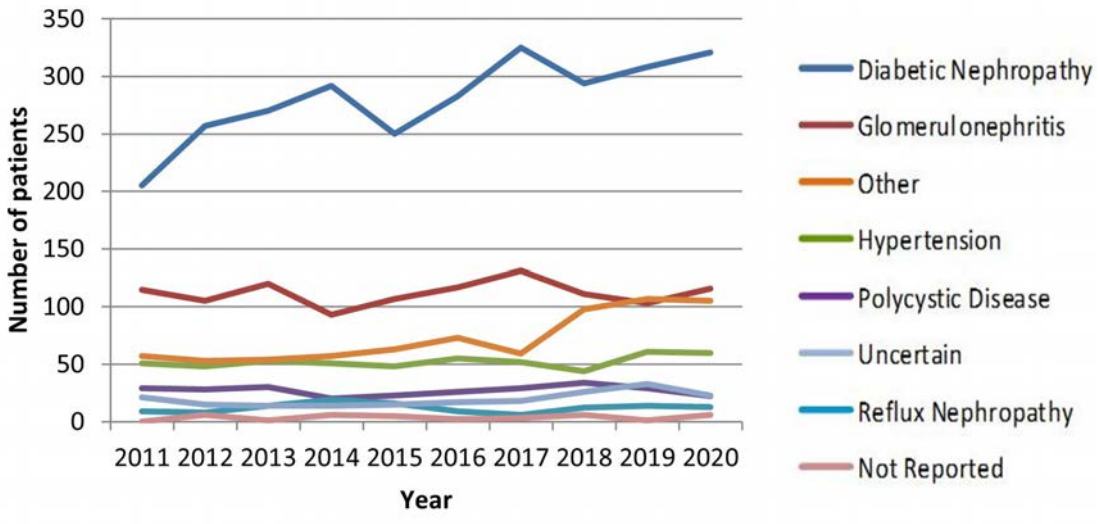
Tolvaptan is a vasopressin 2 receptor antagonist that acts on collecting ducts to ameliorate the effect of cyclic AMP, which would otherwise stimulate the secretion of fluid.[20] Clinically, this causes a picture of polyuria due to loss of free water. The TEMPO 3:4 trial showed tolvaptan slowed decline in renal function and reduced kidney growth in patients with well-preserved renal function (estimated glomerular filtration rate (eGFR) >60m/min/1.73m^2).[21] The REPRISE trial also demonstrated tolvaptan preserved renal function in patients with more advanced renal impairment (eGFR 25–65ml/min/1.73m^2).[22]

However, tolvaptan is not without side-effects and not all patients with ADPKD will progress to ESKD. Key side effects include thirst, polyuria and nocturia, as would be expected with its aquaretic profile. Idiosyncratic hepatic dysfunction also occurs, and liver function must be closely monitored in patients. In addition, the long-term effects of tolvaptan are uncertain, with follow up out to five years suggesting benefit.[23] Nevertheless, tolvaptan is the first medication licensed to use as directed therapy for PCKD and is now available in a number of counties (Table 1).

The various current guidelines for tolvaptan use in ADPKD target patients with substantial current kidney enlargement, and (in individuals > 45 years) historical evidence of significant previous kidney function decline over time.[10,19,26] The studies have shown useful delay in progression to, but not prevention of eventual ESKD.[21–24] It is possible that in the future, new protocols may be devised targeting at an earlier stage in their natural history and achieving the "holy grail", of long-term normal kidney function.[27]

In December 2016, a clinician application for tolvaptan for ADPKD was made to Te Pātaka Whaioranga, The Pharmaceutical Management Agency (PHARMAC), with the Nephrology subcommittee recommending that tolvaptan for patients with be listed on the pharmaceutical schedule with a high priority if a registered prod-

Figure 1: Primary renal disease of patients starting dialysis in Aotearoa New Zealand.



(Adapted from ANZDATA).[1]

Table 1: Selected countries funding tolvaptan for therapy of polycystic kidney disease (PCKD).[24–26]

Country	Submission date	Status
United States of America	March 2013	Approved April 2018
Japan	May 2013	Approved March 2014
European Union	November 2013	Approved May 2015
Canada	March 2014	Approved February 2015
Switzerland	October 2014	Approved April 2016
Republic of Korea	June 2015	Approved December 2015
Australia	February 2016	Approved March 2017

Figure 2: Tolvaptan – recommended special authority criteria.[28]

Initial application—(autosomal dominant polycystic kidney disease) from a renal physician or on the recommendation of a renal physician. Approvals valid for three months for applications meeting the all of the following criteria:

1. Patient has a confirmed diagnosis of autosomal dominant polycystic kidney disease (ADPKD);
2. Patient has an eGFR of between 25mL and 65mL/min/1.73m^2 at treatment initiation;
3. Patient's disease is rapidly progressing, defined as either:

a. A decline in eGFR of greater than or equal to 5mL/min/1.73m^2 within one year; or

b. An average decline in eGFR of greater than or equal to 2.5mL/min/1.73m^2 per year over a five-year period.

Note: Tolvaptan must be initiated and monitored under the supervision of physicians with expertise in managing ADPKD, and a full understanding of the risks of tolvaptan therapy including hepatic toxicity and monitoring requirements (liver function tests are required prior to tolvaptan initiation, monthly for the first 18 months and three-monthly thereafter; concurrent monitoring for symptoms of possible liver injury is recommended).

Renewal—(autosomal dominant polycystic kidney disease) from a renal physician or on the recommendation of a renal physician. Approvals valid for three months for applications meeting the following criteria:

All of the following:

1. Patient has previously received tolvaptan for confirmed ADPKD;
2. The treatment remains appropriate and the patient is benefitting from treatment;
3. Patient has not developed end-stage renal disease (defined as an eGFR of less than 15mL/min/1.73 m^2);
4. Patient has not undergone a kidney transplant.

Note: Tolvaptan must be monitored under the supervision of physicians with expertise in managing ADPKD, and a full understanding of the risks of tolvaptan therapy including hepatic toxicity and monitoring requirements (liver function tests are required monthly for the first 18 months and three-monthly thereafter; concurrent monitoring for symptoms of possible liver injury is recommended).

uct becomes available. Tolvaptan has been Medsafe registered in Aotearoa New Zealand since May 2019, and was recommended for use in selected patients with ADPKD subject to special authority criteria in August 2019 (Figure 2).[28]

Despite these clinician and committee recommendations, subsidised access to Tolvaptan has not occurred. The Samsca brand can currently be brought in (15mg or 30mg tablets) which cost $2680 per pack of 10—not including GST or mark up. Tolvaptan is typically started at twice daily doses of 45mg and 15mg and increased to a tolerated maximum dose of 90mg and 30mg. Approximately 55–60.6% of patients are usually able to tolerate the maximal dose.[21,22] Thus, the minimum cost for a starting dose of tolvapatan is over $35,000 per annum. The alternative is for dialysis (~$70,000 per year) or kidney transplantation (~$100,000 initially and then ~$13,000 per year).The Te Pātaka Whaioranga Nephrology subcommittee noted in their review that the cost of dialysis, which would be postponed rather than not required, would generally be balanced against the cost of treatment with tolvaptan.[28] The National Institute for Health and Care Excellence (NICE) and Australian Pharmaceutical Benefits Scheme (PBS) concluded the cost-effectiveness of tolvaptan in patients with stage 2–3 chronic kidney disease with rapid disease progression based on their cost effectiveness analysis, and this aligns with the proposed special authority guidelines proposed.[29,30]

The patient's voice

As one of five whānau members spanning over four generations in two countries with confirmed ADPKD, the impact and burden of the disease has been and continues to be significant. The disease burden on my whānau has included early death, increased morbidity and whānau suffering.

The disease burden of ADPKD is reflected in the health system through increased hospital admissions, costly dialysis and transplant. The financial impact is considerable.

Funding tolvaptan would greatly diminish the impact and burden of ADPKD on individuals in Aotearoa New Zealand, their whānau and the health system. The hope of not needing dialysis and/or transplant for those individuals who are eligible for this therapy would be life changing.

Conclusion

ADPKD disease is a common cause of kidney failure. Selected therapy is available to slow the progression of this disease. The authors call upon Te Pātaka Whaioranga to urgently complete negotiations to support funding for tolvaptan in selected patients.

COMPETING INTERESTS
Nil.

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Neurotuberculosis with paradoxical reaction treated with infliximab: case report and literature review

Grace Chia, Tait Bartlett, Cindy Towns, Timothy Blackmore

ABSTRACT

Paradoxical reactions are immune-mediated disease exacerbations that can occur in *Mycobacterium tuberculosis* (TB) following initiation of treatment. They are rare, challenging to manage and often fatal. We present a case of neurotuberculosis in a young woman, complicated by a paradoxical reaction in which infliximab was trialled without success. This case demonstrates the severity of presentation that can occur in neurotuberculosis, and the complications that paradoxical reactions can present. It also highlights the difficulty of delivering palliative care within the context of communicable disease with challenges posed by both TB and the COVID-19 pandemic.

Mycobacterium tuberculosis (TB) remains a major cause of death worldwide, with central nervous system (CNS) involvement associated with higher mortality.[1–2] Paradoxical reactions are rare complications of treatment that are challenging to manage. We describe a patient with neurotuberculosis who developed a fatal paradoxical reaction whilst receiving anti-TB treatment, which led to difficult issues regarding palliative care of a communicable disease.

Case report

A 44-year-old Thai woman living in New Zealand for over 10 years presented to Wellington Hospital with two-week history of headaches, abdominal pain and fevers. At presentation, she was found to have anisocoria, mild left hemiplegia, and ataxia but no confusion. Her medical history was unremarkable, and the initial diagnosis was thought to be an intracerebral bleed. A HIV test was negative. Chest X-ray and brain computerised tomography (CT) were initially unremarkable, but cerebrospinal fluid (CSF) analysis showed $189x10^6$ white blood cells/L (67% mononuclear cells), an elevated protein of 5.08g/L and low glucose 2.4mmol/L. Initial opening pressures were unfortunately not completed on the first lumbar puncture (LP) but were subsequently measured at 50mmHg. Standard oral four-drug anti-TB treatment with dexamethasone 0.4mg/kg was commenced after acid-fast bacilli detection in the CSF. [3] Fully susceptible MTB was subsequently cultured in the CSF and sputum.

Her cognition remained normal initially but on day three she became minimally responsive (GCS 8/15) with persistent fevers and new right oculomotor nerve palsy. Hydrocephalus was demonstrated on CT scan, requiring placement of an external ventricular drain. Subsequent magnetic resonance imaging (MRI) revealed leptomeningitis, multiple tuberculomata (left frontoparietal, right temporal, left cerebellar, right medulla), vasculitic infarcts and miliary lung involvement. There were no other pathogens identified. She also developed seizures and was started on levetiracetam. A paradoxical reaction was diagnosed which was managed with five-day course of pulse 1g intravenous methylprednisolone, followed by 5mg/kg infliximab infusions.[4] A follow-up CSF culture was negative for growth of MTB four weeks later.

There was no significant improvement in clinical status despite four weeks of anti-TB treatment and management of the paradoxical reaction of the CNS; the patient remained bed bound, minimally responsive, and reliant on nasogastric (NG) tube for feeding and administration of medications. She was fully dependent on nursing care. It was felt that a transition to a palliative approach would be appropriate. Most of her family were overseas with international travel not being possible due to COVID-19 restrictions. Complex family meetings regarding prognosis and withdrawal of treatment were held over video conference with translators.

Withdrawal of treatment decisions were further affected by the communicable nature of TB. A conservative approach was taken for the duration of TB treatment because of the uncertainty about

how long she would remain alive, and due to the need for placement in a long-term care facility. Four months of anti-TB treatment had been given, and the infectious disease team and Medical Officer of Health agreed that treatment had been sufficient to no longer pose a transmission threat even if she survived for several weeks—and the NG tube was therefore removed. Nine days following cessation of treatment, the patient passed away in residential care.

Discussion

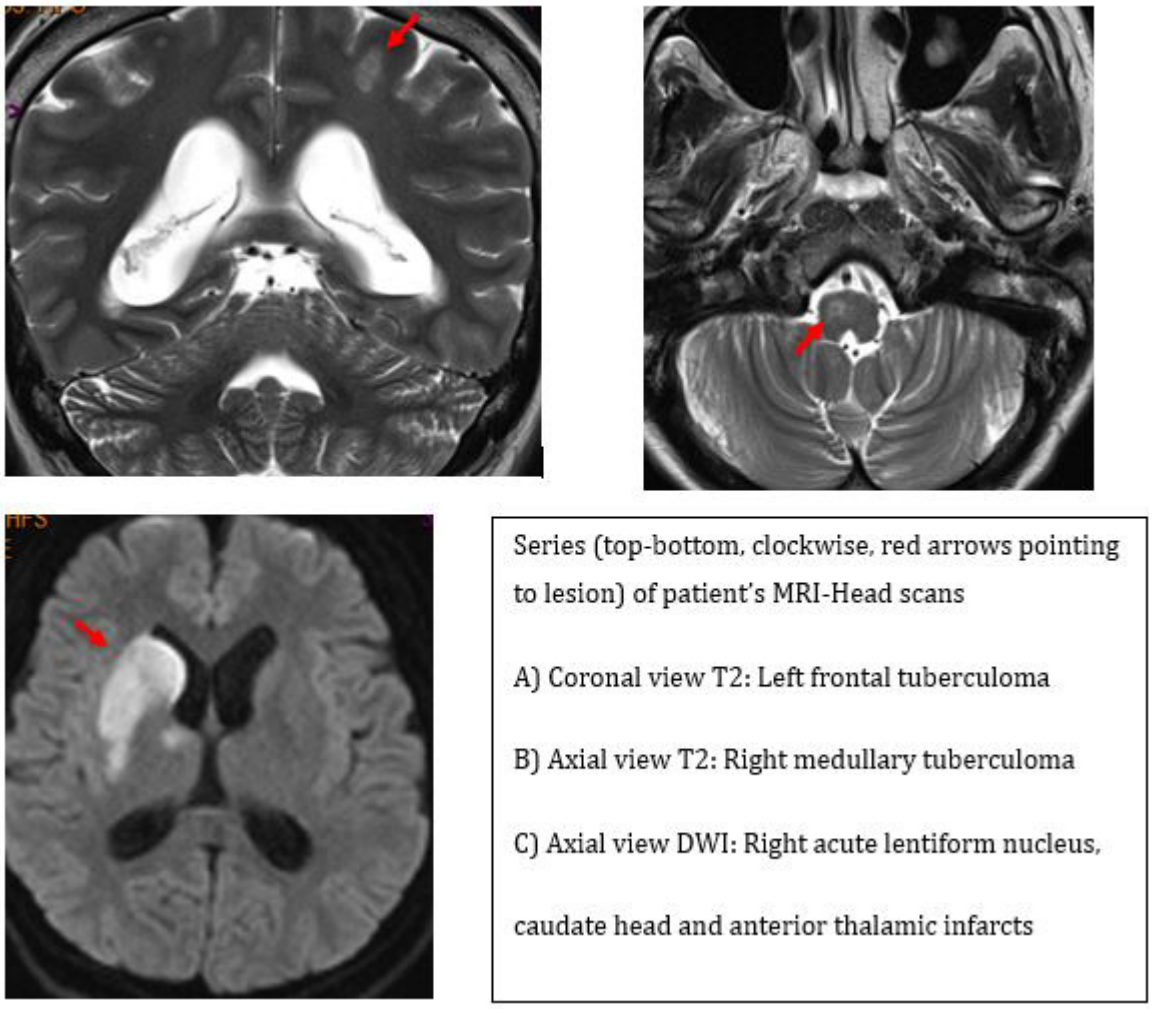
This case demonstrates how severe neurotuberculosis can be at presentation, and of its associated complications. Quantifying and communicating prognosis to patients and family members at baseline may be difficult. This can be guided by bedside scores such as MASH-P (baseline Modified Barthel's index (M), age (A), stage of TB meningitis (S), hydrocephalus (H), papilledema (P)); this patient had an initial score of 4/10, carrying a 10% predicted six-month mortality.[4] Paradoxical reactions are often life-threatening, especially with CNS involvement, and remain rare with only a small number of case studies documenting the use of infliximab.[5] This inflammatory response occurs in response to dying mycobacteria and can present with fever, hypoxia, lymphadenopathy, and new organ involvement. Tumour necrosis factor alpha (TNF-α) is central to the host response to TB infection. Infliximab is a monoclonal antibody to TNF-α and acts to prevent further formation without the long-term toxicity of systemic corticosteroids.[6] Unfortunately, the patient did not significantly recover at any stage despite anti-TB treatment and aggressive management of the paradoxical reaction.

The management of this patient also highlights the complexity that can arise when applying a palliative model of care to communicable disease and differing cultural perspectives. Given the uncertainty of a slow neurological recovery and the slow decline, it was difficult for her family to come to terms with a transition to palliative care, and for the medical team to ascertain the urgency for end-of-life planning. Buddhism is the predominant world view in Thailand, and it is very important within Thai culture for family to be with the patient during death to help ensure a peaceful passing.[8] For significant family members to be separated with no chance of visiting, and during a time when active treatment was withdrawn, was distressing to all involved. Removal of an NG tube is routine in terminal care as it can be intrusive and distressing. Continuation of enteral feeding and fluids via NG inappropriately prolongs life where that is no longer the goal.[7] However, an NG tube can also be a route of administration for medications for TB and prevention of seizures. Without treatment, a TB patient could become infectious again, develop drug-resistant TB and put others at risk. This would constrain visiting, increase barriers to care and compromise discharge planning.[9–10] The patient spent four months in hospital with no improvement but was deemed to have received enough treatment to render her non-infectious. She was transitioned to subcutaneous midazolam for seizure prevention and palliated following discussions with family.

Finally, the management of this case demonstrates the significant indirect impacts COVID-19 can have on patient care. New Zealand has been celebrated for its response to the pandemic with comparatively few deaths and hospital admissions.[11] Less obvious have been the indirect impacts of the pandemic on patients and their families. This was just one of numerous examples throughout our healthcare system where a family was prevented from being with their loved one at times of crisis and made repatriation impractical. Although online communication tools have enabled family to see and speak to their relatives, they are a poor substitute for in-person conversation and human touch.

This report highlights the complications that can occur in TB even in the absence of drug resistance. It demonstrates the complexities of palliative care in the context of communicable disease, with impact from both TB and COVID-19 in this case, and the balance that must be struck between public health and personal needs. The ultimately fatal illness of this young woman is also a reminder of how important ongoing global efforts are in the prevention and treatment of infectious disease.

Figure 1: Series of patient's neuroimaging.



Series (top-bottom, clockwise, red arrows pointing to lesion) of patient's MRI-Head scans

A) Coronal view T2: Left frontal tuberculoma

B) Axial view T2: Right medullary tuberculoma

C) Axial view DWI: Right acute lentiform nucleus, caudate head and anterior thalamic infarcts

COMPETING INTERESTS
Nil.

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Visual recovery following surgical intervention for pituitary apoplexy correlated with pre-operative optical coherence tomography

Vidit Singh, Richard Holmes

ABSTRACT

Pituitary apoplexy is a rare but potentially fatal endocrinological emergency which can be difficult to diagnose as presenting symptoms vary significantly. Optimal management requires early diagnosis and collaboration between ophthalmology, endocrinology and neurosurgical services.

We present a case of pituitary apoplexy in a 52-year-old Caucasian female who was referred by her optometrist to Palmerston North Hospital Eye Clinic with a three-week history of sudden onset moderate bifrontal headaches, two weeks of non-specific peripheral visual changes and dense bitemporal inferior quadrantanopia on formal visual field testing. Ocular motility and slit lamp examination were unremarkable and retinal nerve fibre layer (RNFL) was relatively preserved on optical coherence tomography (OCT). MRI demonstrated a haemorrhagic pituitary macroadenoma elevating and compressing the optic chiasm without cavernous extension. Blood tests revealed mild hypothyroidism, hypocortisolism, hypogonadotropism and hyperprolactinaemia.

The patient was commenced on hydrocortisone and levothyroxine replacement and proceeded for urgent transsphenoidal tumour resection at Wellington Regional Hospital. Histology revealed a non-functioning macroadenoma. The patient was asymptomatic and visual field tests had normalised three weeks post-operatively. Six weeks post-operatively, thyroid function and cortisol levels were normal and replacement therapies were ceased.

Pituitary apoplexy results from infarction or haemorrhage of the pituitary gland, most commonly in the presence of an underlying pituitary adenoma.[1–3] As many pituitary adenomas are asymptomatic, pituitary apoplexy is often the first clinical manifestation.[1,4] Pituitary apoplexy occurs more commonly among macroadenomas (>10mm size) than microadenomas, though there remains debate over relative frequency among functioning and non-functioning macroadenomas.[1,3,5,6]

Predisposing factors for pituitary apoplexy include systemic hypertension, major surgery, pituitary surgery or pituitary-involving radiation therapy, head trauma, coagulopathies, dynamic pituitary function testing, high serum oestrogen, pregnancy/delivery and certain medications (including dopamine receptor agonists, ISMN, chlorpromazine, GnRH agonists and clomiphene). However, pituitary apoplexy may occur in the absence of any risk factors.[1,3,7,8]

Estimates of the incidence of pituitary apoplexy among patients with pituitary adenomas vary between 2% and 21%.[1,6,9,10] Incidence of pituitary apoplexy is highest in the fifth and sixth decade of life, with a slight male preponderance estimated between 1.1:1 to 3:1.[1,3,11] Some studies suggest subclinical pituitary apoplexy may be more common among females.[11]

Presenting symptoms vary significantly depending on severity, though often include headaches, nausea/vomiting and bitemporal visual field defects. Decreased visual acuities, ocular motility dysfunction, reduced level of consciousness, fevers and meningism may also occur. Diagnosis is confirmed by CT or MRI head. As endocrine abnormalities are common and potentially life-threatening, a pituitary function blood panel is recommended as part of initial work-up.[1,3,11]

Our case highlights the importance of collaboration between Ophthalmology, Endocrinology and Neurosurgical specialties in the effective diagnosis and management of pituitary apoplexy. The importance of visual field assessment as part of work-up for patients presenting with headache and visual disturbance is demonstrated. Treatment options for pituitary apoplexy and predictive factors for visual recovery including preoperative optical coherence tomography (OCT) are discussed.

Case presentation

A 52-year-old Caucasian woman was referred by her Optometrist to Palmerston North Hospital Eye Clinic with a three-week history of sudden onset moderate bifrontal headaches, two weeks of visual disturbance, which was described as peripheral "mottling" or "tunnelling", and dense bitemporal inferior quadrantanopia on formal visual field testing (Figure 1).

The patient's medical history was remarkable for pre-diabetes (HbA1c 44mmol/mol), hypertension, mild asthma and a previous left lower limb varicose vein treated by surgical stripping. The patient's menopause occurred three years prior. Medications included cilazapril 5msg PO OD, amlodipine 5mg PO BD and metformin 850mg PO BD. The patient had no known adverse medication reactions.

Upon examination, the patient was alert, oriented and appeared well. The patient was afebrile with a blood pressure of 142/78mmHg, and otherwise normal vitals. Visual acuities with glasses were 6/12 on the right and 6/30 on the left with no improvement with pinhole. Intraocular pressures were 14mmHg in both eyes with iCare tonometry. Ocular alignment and extraocular movements were normal—no ptosis, lid retraction or nystagmus was present. Pupils were equal and reactive with no relative afferent pupillary defect (RAPD), and colour vision was full on testing with Ishihara plates. Cranial nerve and limb power examinations were normal.

Slit lamp and dilated fundus examinations were normal. In particular, no ocular media opacities were present, and the optic nerves and maculae appeared healthy and well-perfused. Repeat formal visual field testing was not performed, given that this had been performed by the Optometrist the day prior. OCT demonstrated relatively preserved retinal nerve fibre layer (RNFL) while Ganglion Cell Layer (GCL) thicknesses were modestly reduced bi-nasally, particularly in the left eye (Figure 2).

Optic chiasmal pathology was suspected, with pituitary macroadenoma being the most likely differential. An MRI of the brain and orbits was requested to investigate further (Figure 3). This demonstrated widening of the sella and erosion of the dorsum sellae, with a heterogenous mass arising from the pituitary fossa, measuring 37x24x25mm with a fluid–fluid level. No normal pituitary tissue was visible, and the pituitary stalk was not identifiable. The lesion was consistent with a haemorrhagic pituitary macroadenoma (pituitary apoplexy) causing elevation and compression of the optic chiasm, without cavernous extension.

Initial blood tests demonstrated mild central hypothyroidism, hypocortisolism and hyperprolactinaemia. FSH of 3.0U/L and LH of 0.6U/L were below normal for post-menopausal state, suggestive of hypogonadotropism. Complete blood count, creatinine and electrolytes, liver function tests, INR, APTT, plasma ACTH, IGF-1 and GH were within normal range (Table 1).

The patient was commenced on Hydrocortisone 20mg PO mane, 10mg midi, 10mg nocte and levothyroxine 50mcg PO OD with endocrinology input. A CT head scan and dedicated pituitary MRI were performed for pre-operative planning, and the patient was referred to the Wellington Regional Hospital Neurosurgery Department. Tumour excision was performed by transsphenoidal approach four days following initial diagnosis. The procedure was uncomplicated, and the patient's recovery was uneventful other than intermittent headaches initially, which were severe at times but gradually settled over the course of two months. Histology showed a benign non-functioning pituitary macroadenoma and post-operative MRI demonstrated a small residual non-enhancing tumour mass present within the sella turcica measuring 16x5 x12mm with unchanged widening of the sella and erosion of the dorsum sellae (Figure 4).

The patient was reviewed in Ophthalmology clinic three weeks post-operatively with visual acuities of 6/4.5 in the right with glasses and 6/9+2 in the left with glasses, pin holing to 6/6+2. Slit lamp examination and dilated fundus examination were once again unremarkable. Formal visual field testing was performed, and demonstrated complete resolution of the inferior-temporal hemianopia in the right eye with a small central visual defect that was deemed artefactual, as it was not reproducible on subsequent testing. A small area of persistent temporal visual field loss was noted in the left eye (Figure 5), which corresponded to nasal GCL thinning on preoperative OCT (Figure 2). The patient's visual acuity and fields remained stable at subsequent follow-ups.

The patient attended follow-up with the endocrinology service six weeks post-operatively. 0900 serum cortisol was 358nmol/L after withholding hydrocortisone for 24 hours and therefore this medication was stopped. Thyroid function tests had normalised, with a T4 of 14.4 pmol/L and TSH of 1.28mU/L, and HbA1c improved to 40 mmol/mol. Therefore, levothyroxine and metformin

Figure 1: Results of Medmont Central Fast Threshold visual field testing by referring optometrist demonstrating dense bi-temporal inferior quadrantanopia, as well as early bitemporal superior field loss. Results were highly suggestive of optic chiasmal pathology.

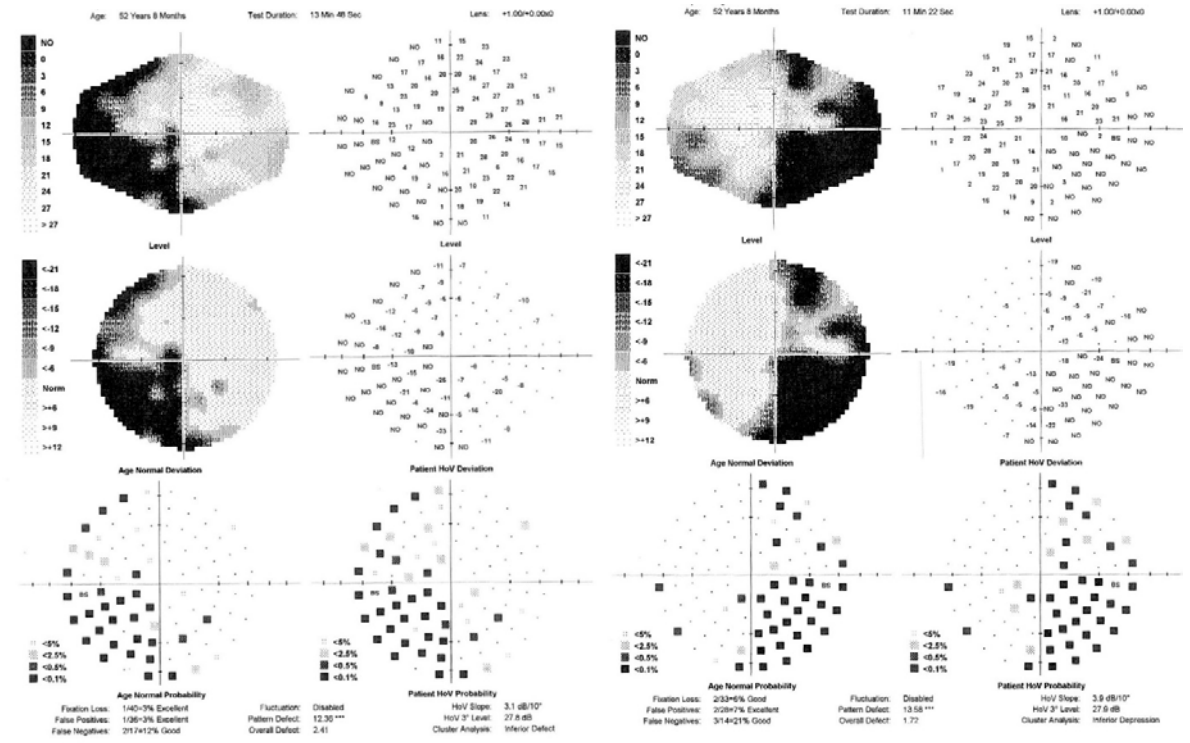
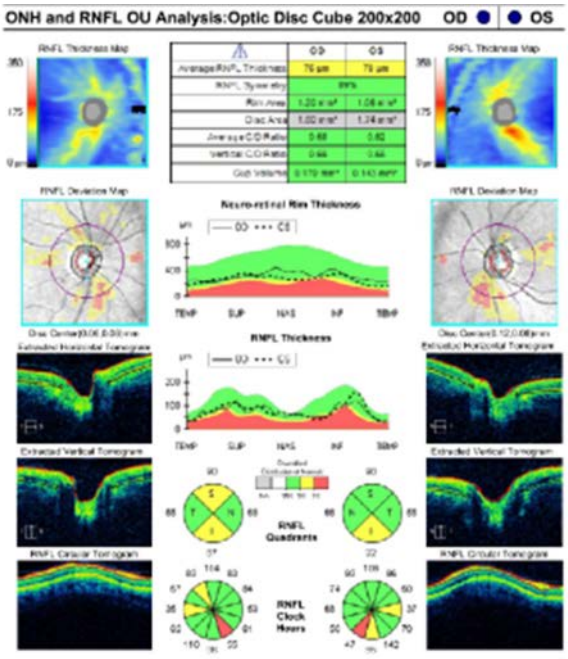


Figure 2: Pre-operative optical coherence tomography (OCT) scans of the retinal nerve fibre layer (RNFL) and ganglion cell layer (GCL), showing subtle generalised bilateral RNFL thinning as well as moderate bi-nasal GCL thinning particularly in the left eye.



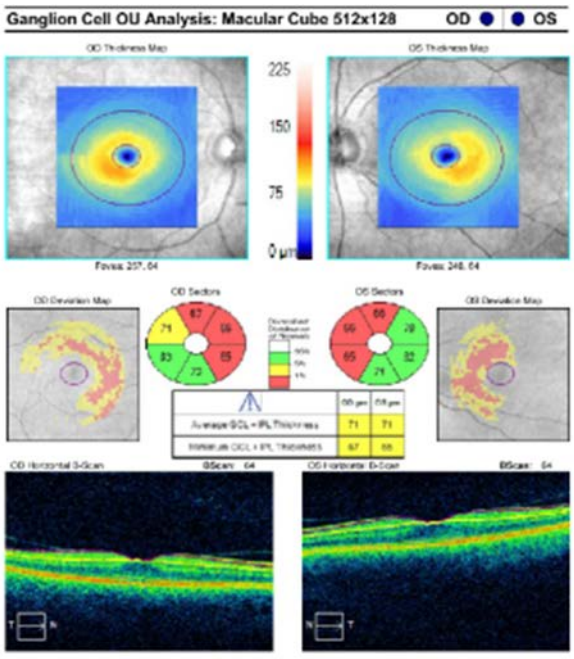


Figure 3: Pre-operative T1 TSE FLAIR Sagittal MRI (left) and T2 TSE Transverse MRI (right) demonstrating a heterogeneous pituitary mass with non-dependent fluid in the anterior mid-portion, consistent with a haemorrhagic pituitary macroadenoma (pituitary apoplexy). Optic chiasmal elevation was present with no cavernous sinus extension.

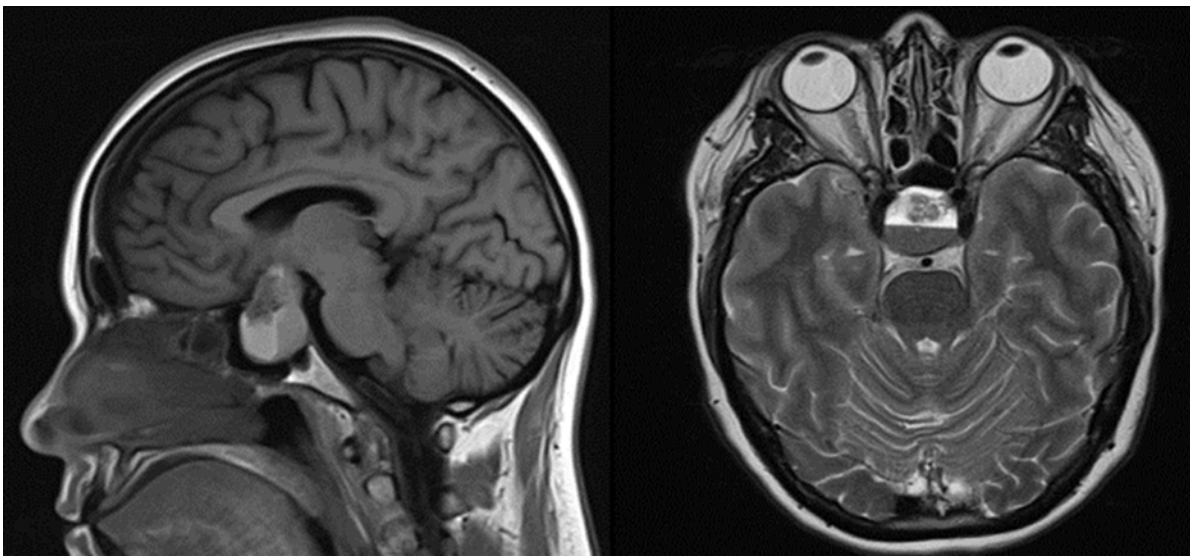


Figure 4: Post-operative T1 TSE Sagittal MRI (left) and T2 TSE Transverse MRI (right), demonstrating small residual pituitary tumour tissue with unchanged widening of the sella and erosion of the dorsum sellae. No elevation of the optic chiasm is seen.

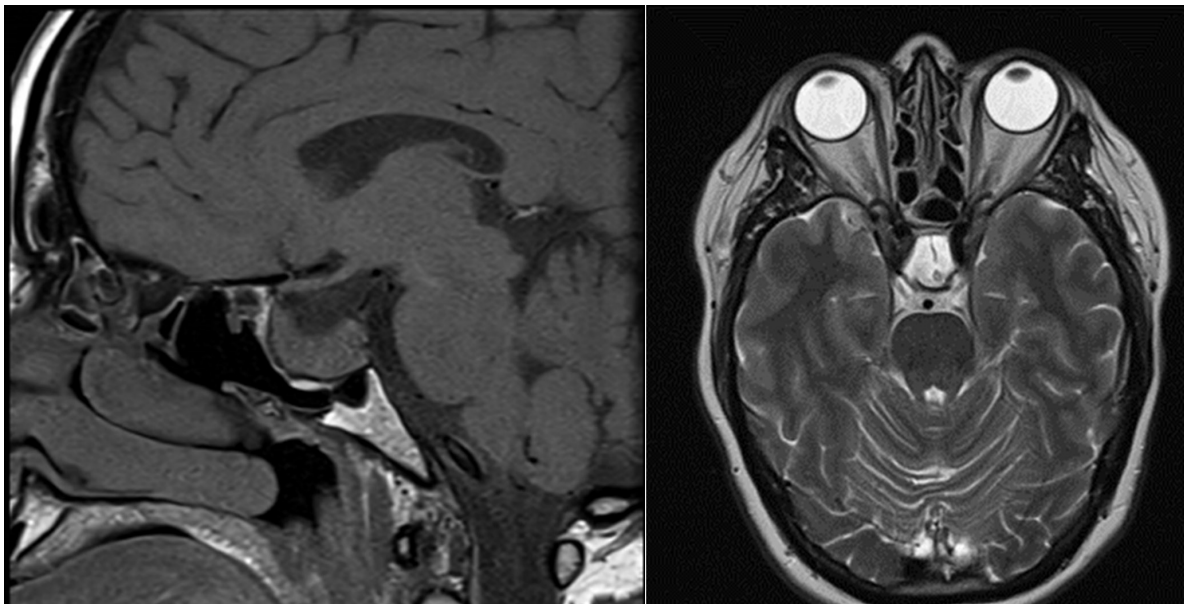
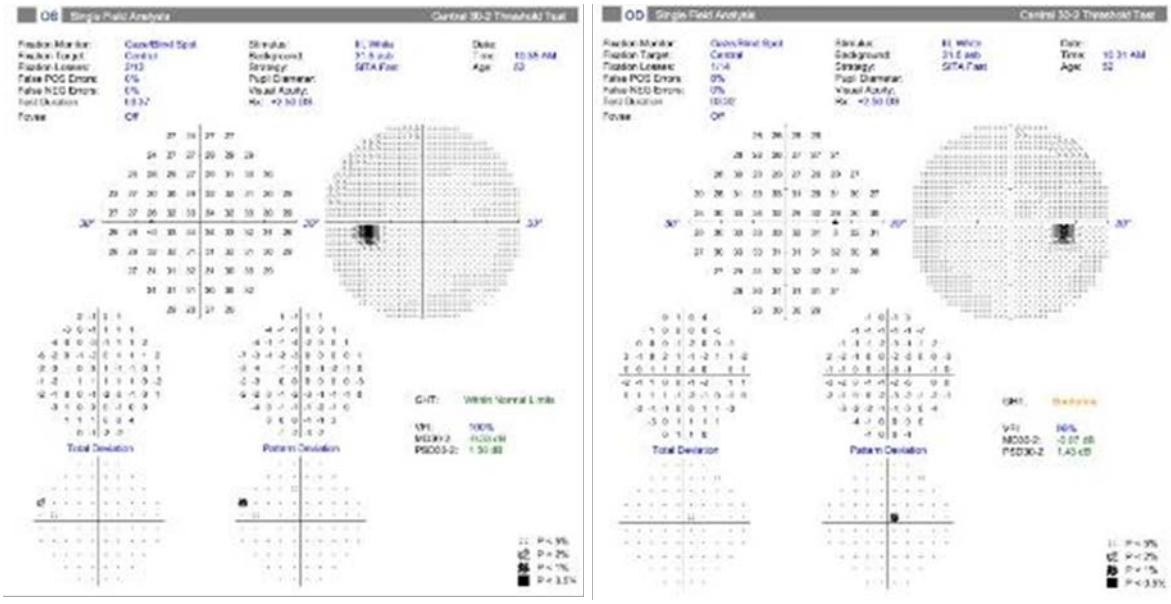


Table 1: Summary of hormone, electrolyte and renal blood results for our case. Hyperprolactinaemia, hypothyroidism and hypocortisolism resolved post-operatively, while mild hypogonadotropism persisted.

	Immediate pre-operative	1 month post-operative	6 weeks post-operative	4 months post-operative	Reference range
Cortisol (0900)	133 (L)	355*	358**		150–550nmol/L
ACTH (Plasma)	5.0	3.4			1.0–12.0pmol/L
TSH	1.36	1.28		2.06	0.27–4.2mU/L
Free T4	6.0 (L)	14.4		12.5	12.0–22.0pmol/L
Free T3	3.6 (L)	4.7			4.0–6.8pmol/L
hGH	0.12	0.12			<6ug/L
IGF-1	58	80			51–190ug/L
Prolactin	566 (H)	211			100–500mU/L
FSH	3.0 (L)	4.1 (L)			26–134U/L
LH	0.6 (L)	1.9 (L)			>20U/L
Oestradiol		<18 (L)			<180pmol/L
HbA1c		40			<41mmol/mol
Creatinine	77	67			45–90umol/L
Sodium	138	141		136	135–145mmol/L
Potassium	4.3	4.4		4.3	3.5–5.2mmol/L
Calcium (adjusted)	2.46	2.45			2.10–2.55mmol/L
Phosphate	1.08	1.16			0.8–1.5mmol/L

ACTH – adrenocorticotropic hormone; TSH – thyroid stimulating hormone; hGH – human growth hormone; IGF-1 – insulin-like growth factor-1; FSH – follicle stimulating hormone; LH – luteinising hormone.
*Cortisol level during replacement hydrocortisone therapy
**Cortisol level 24 hours after hydrocortisone withheld

Figure 5: Results of Zeiss HFA 30-2 SITA-Fast visual field testing one month post-operatively, demonstrating near-complete resolution of bitemporal visual defects. A small area of left temporal field loss was present and persisted on visual field testing at subsequent follow-ups.



were also stopped. Repeat thyroid function tests remained in the normal range six weeks after stopping levothyroxine.

Discussion

Clinical manifestations of pituitary apoplexy depend on the extent of haemorrhage, damage to the normal pituitary tissue and compression of surrounding structures such as the optic chiasm, hypothalamus, cavernous sinus and its contents.[2,3] Severe cases typically present with sudden onset severe headache followed by some combination of nausea/vomiting, ophthalmoplegia, visual loss, fevers, meningism or decreased level of consciousness occurring over hours to two days and can be life-threatening. However, symptoms in mild cases may be less pronounced and may have an insidious onset, as in the current case.[2,10] The differential diagnoses for patients presenting with headache and non-specific peripheral visual disturbance is wide and includes migraine, acute angle closure glaucoma, intracranial hypertension (idiopathic or otherwise), temporal arteritis, and optic neuritis among others. Visual field testing is fast, inexpensive and often useful in localising the area affected. In our case, characteristic bi-temporal visual field loss, particularly inferiorly, was highly suggestive of a pituitary lesion causing chiasmal compression. This resulted in prompt pituitary blood panel, MRI and early treatment.

There remains debate over the role and optimal timing of surgical decompression in pituitary apoplexy. No prospective trials exist due to the rarity of pituitary apoplexy. Case series and reports comparing conservative management and early decompression have varying conclusions, though significantly better visual outcomes have been demonstrated with surgical decompression compared to conservative management in patients with severely reduced visual acuity or visual field defects.[1,3] The UK guidelines for management of pituitary apoplexy advise that surgical decompression should be performed by an experienced pituitary surgeon within seven days of symptom onset in patients "with severe neuro-ophthalmic signs such as severely reduced visual acuity, severe and persistent or deteriorating visual field defects or deteriorating level of consciousness."[1] Reduced visual acuity and severe visual field loss were indications for early surgical decompression in the current case.

Pre-operative visual field defect, visual symptom duration and extensive retinal nerve fibre layer (RNFL) and ganglion cell layer (GCL) thinning on optical coherence tomography (OCT) are predictive factors for poor visual field recovery after surgical excision of pituitary adenoma.[12–15] Although these factors were identified in cases of adenoma without apoplexy, it is reasonable to

expect that such factors are relevant in pituitary apoplexy, given that visual field impairment is caused by direct compression of the optic chiasm in both conditions. In the current case, short visual symptom duration (two weeks) and preserved RNFL thickness on preoperative OCT suggested the potential for significant post-operative visual recovery despite a dense preoperative visual field defect. Nasal GCL thinning on pre-operative OCT, particularly in the left eye suggested the possibility of some persistent field loss, as was noted in the left temporal periphery post-operatively.

Pituitary apoplexy results in ischaemia, irreversible loss of healthy pituitary tissue and may lead to pituitary insufficiency. Some form of endocrine dysfunction is present in 80% of cases—most commonly deficiencies of growth hormone, gonadotropins and ACTH, hypothyroidism and hyperprolactinaemia.[1,3,11] Hypocortisolaemia results from impaired pituitary ACTH secretion and may cause electrolyte disturbance and haemodynamic instability, which may be life-threatening. Commencement of empiric hydrocortisone replacement therapy with Endocrinology input is recommended in cases of haemodynamic instability, altered level of consciousness or significant visual impairment. Patients with 09:00 serum cortisol less than 550nmol/L should be considered for hydrocortisone replacement therapy.[1] Hypocortisolism, hypogonadotropism and hypothyroidism were present in the current case pre-operatively without haemodynamic instability or hyponatraemia. Appropriate hydrocortisone and levothyroxine replacement were commenced with input from endocrinology. Hydrocortisone and levothyroxine replacement therapies were ceased six weeks following early surgical decompression, as the patient regained adequate pituitary function. This is consistent with findings from Liu et al, which demonstrated at least partial recovery of hormone deficiency after early surgical decompression.[11]

The diagnosis and management of pituitary apoplexy can be challenging. Patients may present acutely unwell or with very few symptoms. Visual field testing is a cheap, non-invasive investigation that can be very useful in identifying pituitary pathology, which may otherwise be missed. Pituitary blood testing is an important part of the initial work-up in cases of suspected pituitary apoplexy, as hormonal deficiencies are common. Serum cortisol testing is of particular importance as untreated hypocortisolism is potentially life-threatening. Significant visual and hormonal recovery may occur following early surgical decompression. The extent of postoperative visual field recovery in pituitary apoplexy may be predicted by similar factors as in pituitary adenoma without apoplexy, though further research in this area is warranted.

COMPETING INTERESTS

Nil.

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Symptomatic vertebrobasilar artery stenosis treated with enoxaparin

Karim M Mahawish

Intracranial artery stenosis is a major cause of stroke worldwide, and is more prevalent in Asian, African and Hispanic populations.[1,2] It is defined as stenosis of an intracranial vessel of at least 50%, and can be diagnosed non-invasively using magnetic resonance angiography (MRA), computed tomography angiography (CTA), or transcranial doppler. In the warfarin vs aspirin for symptomatic intracranial stenosis randomized controlled trial (WASID),[3] warfarin was associated with more adverse events and provided no benefit over aspirin. A recent Cochrane Review found that endovascular angioplasty/stenting was associated with higher complication rates than best medical management.[2] Thus, intensive therapy with antiplatelets, statins and antihypertensives are the mainstay of treatment. Despite these measures, stroke recurrence rates remain high at 12.2% per annum.[4] Symptomatic vertebrobasilar stenosis is associated with a higher rate of stroke recurrence than anterior circulation stenosis.[5] A *post hoc* analysis of the WASID trial suggested that warfarin may be more effective in this subgroup of patients.[5] There is clinical equipoise on the best treatment strategy for patients with recurrent events despite best medical management. Here, we present two haemodynamically stable patients with vertebrobasilar stenosis, and with recurrent events on intensive medical therapy.

Case one

A 79-year-old New Zealand European female with a history of hypertension on amlodipine 10mg once daily (OD) presented with two episodes of transient diplopia and left hemiparesis. On arrival, neurological examination was unremarkable. Blood markers were unremarkable with a C-reactive protein of 3.2mg/L and normal complete blood count. CT and CTA of the brain demonstrated an irregular stenotic distal right vertebral artery (Figure 1a). Aspirin (300mg loading, 100mg OD thereafter), clopidogrel (300mg loading, 75mg OD thereafter) and atorvastatin 80mg OD were initiated. Two days later, she had a recurrence of her symptoms. Brain imaging excluded acute infarction or hemorrhage, but persistent vertebral stenosis. Antiplatelets were discontinued and she was started on a heparin infusion adjusting as per activated partial thromboplastin time, switching to therapeutic enoxaparin (1.5mg/kg/day) the following day. We continued this treatment for one month, before switching to aspirin and clopidogrel for a further two months, then clopidogrel monotherapy. She remained asymptomatic two years later.

Case two

An 87-year-old New Zealand European lady presented with transient diplopia and left hemiparesis. Past medical history notable for hypertension. On arrival, she was neurologically intact. MRA brain demonstrated a critically stenosed/occluded basilar artery (Figure 1b) and a small right occipital lobe acute infarct. She was commenced on clopidogrel and aspirin (as per the regimen described earlier) and atorvastatin 80mg OD. Four days later, she deteriorated with dysarthria, hemiparesis, and tongue deviation. CT brain imaging was unremarkable. She was started on intravenous heparin for 24 hours, then switched to subcutaneous enoxaparin (1.5mg/kg/day). She remained neurologically stable and follow-up brain imaging three weeks later demonstrated improved flow within the basilar, however distal vertebral plaques persisted (Figure 1c). During this time her hemiparesis improved, and at time of discharge three weeks later was independently mobile with a walking frame. She was switched to clopidogrel and aspirin, and remained asymptomatic four months later.

Discussion

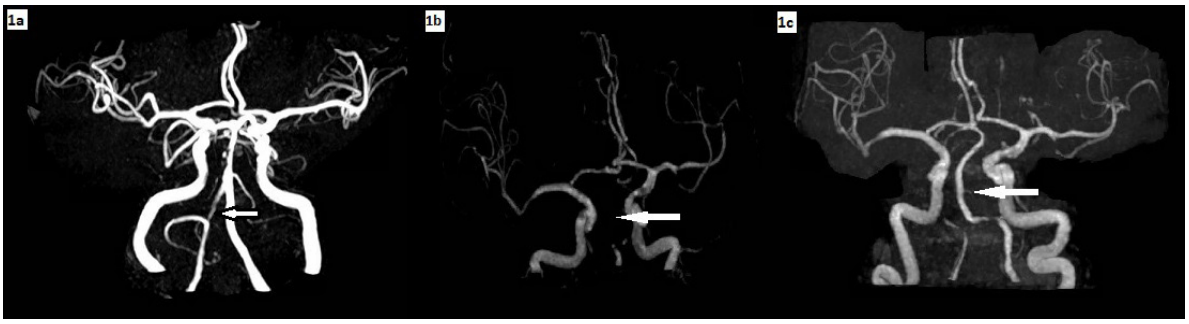
Here we present two patients with vertebrobasilar stenosis failing intensive medical therapy who responded favourably to therapeutic anticoagulation. Anti-Xa monitoring was not required, in accordance with guidelines.[6] Based on our experience, we have found this approach to be highly effective in

preventing recurrent stroke without major bleeding events.[7,8] Intracranial stenting remains a treatment option in patients refractory to medical therapy.

Patients presenting acutely with vertebrobasilar occlusion should be considered for treatment with intravenous thrombolysis and/or clot retrieval. The recently presented randomised control trial Endovascular Treatment for Acute Basilar Artery Occlusion trial (ATTENTION) demonstrated lower rates of disability and mortality with the latter.[9] In those ineligible for hyperacute treatments, heparinisation has a role.

Although WASID found that anticoagulation was ineffective in intracranial stenosis, our two patients seem to have responded well to the introduction of heparin. We used a short duration of anticoagulation thereby firstly, preventing further artery to artery embolisation while allowing plaque stabilisation to occur and secondly, minimising the risk of bleeding from chronic anticoagulation. Patients in the warfarin arm in WASID were in therapeutic range less than two thirds of the time.[3] Using standard dosing enoxaparin in our patients (after unfractionated heparin in first 24 hours) we would expect effective anticoagulation. Treatment with direct oral anticoagulation may be equally efficacious and investigation in larger trials is warranted.

Figure 1: a) CT angiography demonstrating critical stenosis of the right distal vertebral artery; **b)** MR time of flight angiography demonstrating absence/poor flow in the basilar artery; **c)** Improving after three weeks of anticoagulation revealing a residual stenosis of the distal left vertebral artery.



COMPETING INTERESTS

Nil.

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New Zealand's first practical demonstration of the telemedicine system specific to ophthalmology: MedicMind teleophthalmology platform

Christopher Robert Giles Arthur, Renoh Chalakkal, Ben O'Keeffe

A recently published review article in Clinical Ophthalmology[1] has foresighted teleophthalmology to play a critical role in ophthalmology management. However, teleophthalmology services in New Zealand are limited. Community medical centres and rural healthcare can be revolutionised with teleophthalmology. Generalists, equipped with a smartphone-based ophthalmoscope and fundus camera alongside an attached smartphone, and housing the proposed portal and internet connectivity, have found this is sufficient to field live ophthalmology consults.

The article[1] provides a sound framework that remarks on an array of ophthalmic clinical categories, where teleophthalmology and artificial intelligence technology have active roles in serving through screening, diagnosing or providing monitoring services. Teleophthalmology has already proven valuable for the following ophthalmic clinical categories: school screening, general eye care, emergency eye care, amblyopia, glaucoma, age-related macular degeneration, diabetic retinopathy, non-diabetic retinal eye disease, oculoplastics, strabismus, and cataracts and retinopathy of prematurity.[1] The published extensive literature review[1] analyses past, present and potential usage of teleophthalmology. Financial cost and a lack of acceptance and awareness for technology are factors underlying why teleophthalmology has not yet been widely implemented.

Recently, an innovative eye care research organisation from New Zealand, oDocs Eye Care, televised New Zealand's first-of-its-kind teleophthalmology infrastructure on 6 May 2021 on national media platforms within New Zealand. The teleophthalmology exhibition had an ophthalmology specialist in an Auckland city office space, using a Samsung S7 tablet with access to 5G internet (Figure 2). The Auckland ophthalmology specialist fielded consecutive live consults with Dunedin ophthalmology specialists (Figure 1). The Dunedin ophthalmology specialists had access to a smartphone-based ophthalmoscope and fundus camera (nun ophthalmoscope and nun IR camera), attached to a smartphone with internet connectivity.[2] The devices used for the trial have been reviewed elsewhere[3–5] and their effectiveness have been studied and reported.

Systematically, three patients were examined after pharmacological pupillary dilation. Live consults were initiated by the doctors at Dunedin Hospital and consult requests were placed in the Auckland ophthalmology specialists' teleophthalmology portal account waiting list. Patient histories were sequentially discussed while an examination was conducted. While, only retinal examinations were conducted, live consults are also effective for evaluating anterior ocular structures.[6] The teleophthalmology concept was successfully showcased, the targeted audience of general practitioners and optometrists were provided with a practical demonstration.

Recently, the demand for teleophthalmology services has increased, largely attributable to the global COVID-19 pandemic where face-to-face consultations were avoided when practical. Geographical barriers have contributed toward healthcare access inequities. While the efficacy of teleophthalmology is still being established, we do hypothesise a reduction in such inequities by implementing a teleophthalmology infrastructure in New Zealand. Other studies would suggest telehealth can achieve a reduction in morbidity through improved quality of healthcare, and educational opportunities and a reduction in costs, time and carbon footprint expended while travelling.[7–10]

The exhibition hosted by oDocs Eye Care was objective proof for the teleophthalmology concept. The exhibition successfully demonstrated how access barriers such as geographical separation and access to a specialist could be overcome; furthermore, there are salvaged opportunity

costs in the form of time and travel expenditure. Further research is needed to establish the cost effectiveness, efficacy and usability of teleophthalmology. There are plenty of opportunities for teleophthalmology infrastructures to be implement within New Zealand, and ultimately, we can improve the ophthalmic care received by the New Zealand public.

Figure 1: A teleophthalmology live consultation using nun ophthalmoscope at Dunedin, New Zealand.

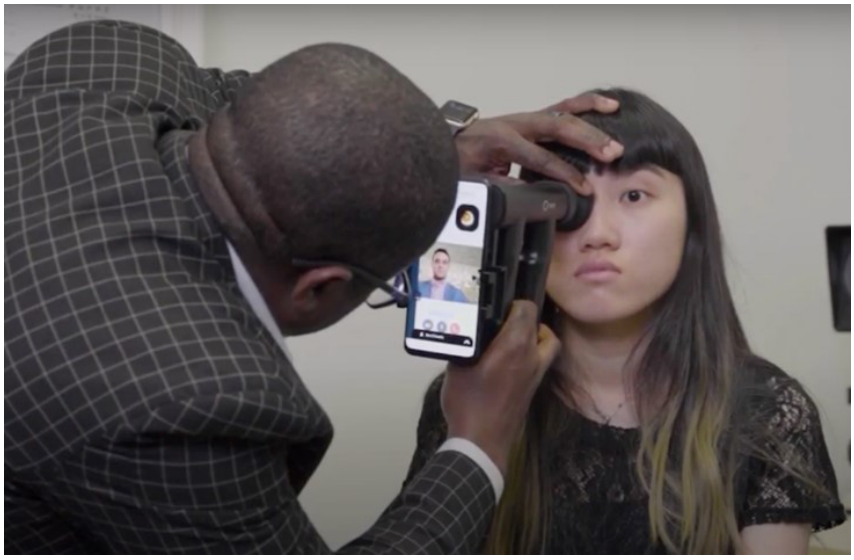
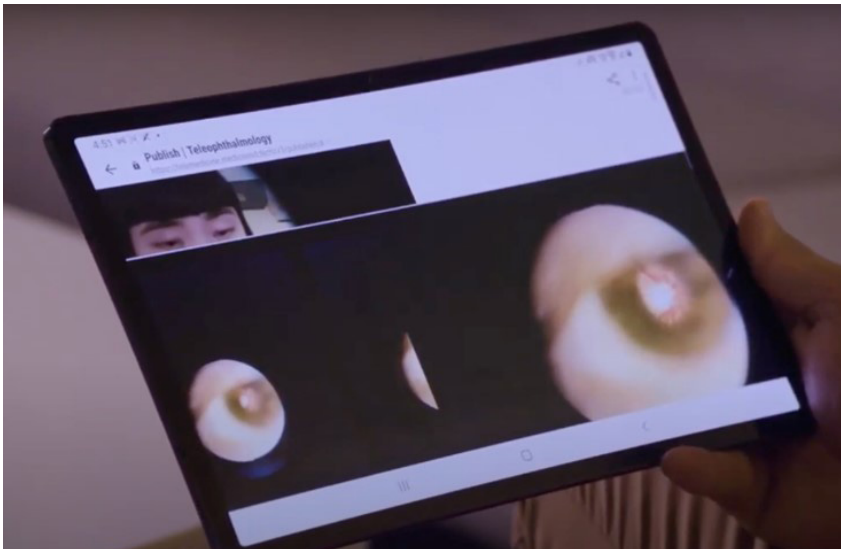


Figure 2: The view from the specialist side in Auckland.[2]



COMPETING INTERESTS
Nil.

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Indoor air quality, largely neglected and in urgent need of a refresh

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Despite people in high- and middle-income countries spending 85–90% of their time indoors,[1] and adults inhaling 11,000 litres of air every day,[2] the health impacts of indoor air quality in Aotearoa New Zealand are barely recognised by Government agencies. While outdoor air quality is managed under the Resource Management Act 1991, which sets National Environmental Standards for outdoor air, no equivalent legislation exists for indoor air quality. The World Health Organization (WHO) recognises that healthy indoor air is a basic human right, stating that the quality of the air people breathe in buildings is an important determinant of health and wellbeing.[3]

According to the Environmental Protection Agency (EPA) in the United States (US), indoor air pollutant levels are typically two-to-five times higher than outdoor levels, and in some cases exceed outdoor levels of the same pollutants by a 100 times.[4] Globally around 2.6 billion people still use solid fuels and kerosene for cooking, and the United Nations notes that indoor and ambient air pollution are the greatest environmental health risk.[5] Time spent indoors combined with higher indoor concentrations of pollutants make the health risks associated with poor air quality usually greater indoors than outdoors.

More recently, the COVID-19 pandemic has highlighted the additional importance of indoor air quality for reducing the transmission of infectious respiratory diseases. While initial public health efforts focused on measures to reduce fomite transmission, such as hand-washing, it is now well-recognised that airborne exposure is the predominant transmission route of SARS-CoV-2 (the virus that causes COVID-19).[6] International consensus on airborne transmission was achieved in part through cutting-edge research conducted by New Zealand experts, but New Zealand health authorities have been slow to apply this key insight beyond border settings.[7] It is imperative that national bodies responsible for the control of the pandemic incorporate the importance of airborne transmission to inform an evidence-based strategy and implement a range of highly effective measures that can prevent airborne transmission of the SARS-CoV-2 virus and other respiratory pathogens, including influenza.[8,9,10,11]

The most effective approach to lowering concentrations of indoor air pollutants, including any pathogens that may be in the air, is usually to increase ventilation,[12] exchanging polluted indoor air for cleaner outdoor air. Understanding and controlling building ventilation can improve the quality of the air we breathe and protect population health, including reducing the transmission of SARS-CoV-2 and other respiratory pathogens.

The European Centres for Disease Prevention and Control have been providing specific guidance on ventilation in the context of COVID-19 since November 2020.[13] While in March 2021, the WHO published a roadmap to ensure good indoor ventilation in the context of COVID-19.[14] The US Centers for Disease Control and Prevention[15] and the EPA[16,17] continuously update advice on ventilation as evidence emerges.

New Zealand's combination of construction styles, climate and geological conditions are unlike any European or North American country. The majority of New Zealand homes rely on natural ventilation and do not have heat-recovery units, and in winter many homes cannot be heated to healthy temperatures. For these reasons, New Zealand-specific solutions are needed, and ventilation improvements should not come at the cost of healthy indoor temperatures. The New Zealand Building Code lags behind other comparable countries, with new buildings still having the potential to be cold, mouldy and unhealthy. While the Building Act 2004 acknowledges health, health is not placed at front and centre of the code. For decades, a range of experts have called for these standards to be improved, but although a recent review was conducted during the COVID-19 pandemic, there appears to be minimal change to ventilation requirements.[18] In addition, sys-

tematic science-based approaches to improve indoor air quality in New Zealand buildings are missing. This gap is in stark contrast to outdoor air quality guidelines, standards, and national monitoring that occurs throughout New Zealand and internationally.

In France, an indoor air quality observatory (OQAI) was established in July 2001 to undertake a national campaign to measure indoor air pollution in homes, schools, office spaces, healthcare and social establishments. This observatory estimated that prior to the COVID-19 pandemic poor indoor air quality in France was contributing to around 28,000 illness episodes and 20,000 deaths per year, representing an annual cost of 19 billion euros (~30 billion NZD, 2022 costs).[19]

Given these issues, we are advocating for the immediate establishment of a long overdue national organisation to address indoor air quality, with a focus on health and wellbeing outcomes. Aotearoa New Zealand urgently needs leadership, coordination, and an adequately resourced national strategy to improve indoor air quality. Such a strategy should set national standards for acceptable indoor air quality, as is already available for outdoor air quality. As well as setting maximum values for particulate matter and chemicals, such as carbon monoxide and nitrogen dioxide, this strategy should also include levels for carbon dioxide as a proxy for ventilation, which will help reduce the transmission of airborne pathogens. Pollutant standards for heating and cooking appliances, particularly for appliances that use unflued gas should also be considered.[20]

An investment in clean indoor air could bring benefits other than reducing COVID-19 transmission, including reduced sick leave and school absenteeism caused by other respiratory infections, particularly influenza and other allergies.[21] Less absenteeism—with associated adverse effect on productivity—could save companies significant costs.[22] Furthermore, there is growing evidence that improved ventilation can improve cognitive functioning of workers and students,[23] which can improve both wellbeing, sleep and productivity.[24] Ventilation can also reduce indoor moisture particularly in homes, which will reduce exposure to respiratory allergens and irritants such as dust mites and mould, resulting in reduced incidence of asthma, rhinitis and allergy symptoms. Improved ventilation would result in a reduction in general practitioner (GP) visits for respiratory illness[25] and a significant reduction in hospitalisations,[26] especially for young children and Māori. We look forward to rapid New Zealand Government action to leverage off the COVID-19 pandemic and make sustained improvements to indoor air quality.

COMPETING INTERESTS
Nil.

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The Spahlinger Treatment for Tuberculosis.

(Read before the Canterbury Division, New Zealand Branch British Medical Association, 2nd March, 1922.)

NZMJ, 1922

Mr. President and Gentleman.—You have no doubt all seen the Spahlinger Treatment for Tuberculosis mentioned in the papers recently, and as I had the opportunity of studying it on two occasions during my recent trip, I thought it might interest you if I made a few remarks about its preparation, the results of its application, and upon some of the cases.

Upon the recommendation of a Harvey Street physician, who gave it as his opinion that although the treatment was not substantiated, he considered there was "something in it," I visited Mr. Spahlinger in Geneva, and as I had heard a good many derogatory remarks about the way his treatment had been introduced to the public, I asked him the reason why it was not in favour with the majority of the profession. He informed me that the "Press," contrary to his expressed wish, had prematurely published the information. Mr. Spahlinger, although not a qualified medical man, has been through the greater part of his curriculum, and has been working at his treatment for about 12 years, during which time he has treated a large number of patients with very satisfactory results. He stated that he was willing to see any doctor who came to Geneva in reference to the treatment, as he did not wish it to be thought that the remedy was a secret one.

In explaining his method he said he was four years and nine months establishing his laboratory, the time being divided up as follows:—

First.—Collection of sputa (about 20 patients were used) and virulisation of the organisms by passage through a series of animals.

Second.—Training the organisms to give up their toxins "in vitro" at various temperatures.

Third.—Immunisation of the horse, which is a slow process. The basis of his treatment is that the tubercular organism has a number of toxins, and the horses are gradually immunised against these.

Fourth.—Preparation of the antitoxin. His great difficulty is to manufacture in large enough quantities, but he reckons that he gets about 1000 doses from each venesection, though I am not able to state the exact amount of blood that he withdraws.

For incubation he uses broth cultures in Roux's tubes, the vaccines being made from the white scum containing the organisms which forms on the top, and the serum from the fluid below.

He considers there are 28 varieties of toxins, and that he had only made a preparation from 25 of these. So far he has been working with a partial serum, but his results are decidedly interesting.

The serum for phthisis is always a mixed one containing streptococcal, staphylococcal, and pneumococcal elements, with that of any other infection thought advisable in a particular case, otherwise the results he stated would be disappointing.

The serum is used in the acute stages only of both phthisis and surgical tuberculosis, the above mixed serum being used in the former, and a mixed bovine and human serum in the latter.

The vaccines are used in the chronic phthisis or the chronic stage after subsidence of temperature, surgical tuberculosis, and in predisposed cases. They are composed of various tuberculin bodies less the ectotoxins removed by free washings.

The average time for immunisation in the phthisical cases is six months, and in surgical tuberculosis about 4–5 months, although these will vary considerably according to the severity of the cases.

Dosage.—The serum is given by the injection usually in doses of 2 c.c. about twice in 7–10 days, but more frequently if required; and in doses of four or five times the amount by the mouth – he has given 20—30 c.c. in one dose. In one case he found it useful as an external application to fisculæ. The vaccines are given hypodermically in 2 c.c. doses once a week (1–1,000,000 of original dilution).

Cost of Production.—As I understood that the upkeep of the laboratory (on account of the number of animals, etc.) was expensive, and that it had taken nearly five years to establish it, I questioned him re the ultimate cost of his preparations, as I felt they would only be procurable by Governments, institutions, or the well-to-do. He replied that he hoped to be able to put them on the market at a reasonable price so that everyone should benefit.

Animals.—In the preparation of his serum and vaccines he has used black and white guinea-pigs, rabbits, monkeys, dark goats, and black and white cows and black horses. He gave it his experience that, although the serum could be prepared from other coloured horses, the pure black gave him the best results. The cows he is now using as controls to test the durability of his preparations. The animals are not kept confined to stalls, but are allowed out freely.

Cases.—Whatever interest there may be in the preparation of the serum and vaccines in this treatment, one cannot but be struck by the clinical results. A great many of Mr. Spahlinger's patients were cases given up by doctors and sanatoria as incurable, and he rather courted such cases, thereby inviting the possibility of failure, as he was anxious to establish the curative effect of his treatment before publishing it. The "Press" unfortunately preceded him, and he was in consequence inundated with requests for treatment before he was ready.

On my two short visits to Geneva, which according to our present conception of what is required cannot be looked upon as an ideal place for the treatment of tubercular infections, I saw several cases—some recovered and others still under treatment.

No. 1.—A boy, 14 years, who has been under treatment for two years and recovered with a large cicatrisation at the left apex, was brought to him originally by his greatest opponent as an incurable case.

No. 2.—A young man – under treatment for the previous 12–18 months – who after ten days' treatment, although improved, was too ill to be propped up for any physical examination, was recovering and able to go to the laboratory for treatment.

No. 3.—An English lady, who had gained nearly two stones in weight in about three months, was also improving, and on my second visit three months later I found her still further improved, although, owing to Mr. Spahlinger's frequent absences she had not had continuous treatment.

No. 4.—A lady medical student from a London Hospital was fully convinced of the improvement she was making under the treatment, and her chart and physical examination bore out her statement.

No. 5.—A British naval officer from an initial pleurisy with effusion, and ill with tuberculosis for years, who had travelled everywhere, was positive he had not had so much relief from any other form of treatment he had been under.

No. 6.—A woman living in Geneva – his first case – had remained well since 1912, after vaccine treatment for tuberculosis glands of the neck with fistulæ and lupus over the upper end of the sternum. The half dozen scars in this case were well healed and in good condition, and the lupus had disappeared, the scar being insignificant.

No. 7.—A man, who had been cured of phthisis three years before was still living in Geneva following out his occupation of a tailor, and had had no relapse. He had no active signs in his lungs.

In London I examined four men who had been treated there before the war by different doctors, and were still there, and had remained well since treatment.

No. 1.—9st. 10lbs. in 1914, had gained 2st. 3lbs., and was very well and acting as "chef" in one of the large hotels.

No. 2.—Was a furniture remover at one of the largest London warehouses, and quite well.

No. 3.— 9st. 7lbs. in 1914, was 13st. 3lbs., and working as a porter in one of the large hotels. This man had had marked symptoms of phthisis, but not one of the serious cases.

No. 4.—Who had both hip and chest infections from 1911–1914 was a bad case. He had been in several hospitals, and was going downhill when the treatment was exhibited. He recovered after two or three months' treatment, and had a subsequent orthopædic operation upon his leg. Although not a robust man, he is well, and is now able to walk with slight assistance from a stick.

Another interesting case – a lady – who had suffered an injury of the patella with secondary infection by Koch's bacillus and ultimate excision of the kneejoint with $2^{1/2}$ inch shortening of the leg, developed renal tuberculosis, and getting no improvement from various forms of treatment, was on the verge of extirpation of one kidney when Spahlinger's treatment was recommended by a London consultant with most satisfactory results. She was under treatment for two years – having two series of injections – twelve each year at weekly intervals. She was nine months in bed, and on getting up it was discovered she now had only $^{1/2}$-inch of shortening in that leg. She was now quite recovered from the renal tuberculosis, and has gone a voyage in lieu of a third course of vaccine treatment.

Another female patient in Paris who was delirious, with pulse 140, temperature 105.8 when the treatment was begun, had four doses of serum daily for about 15 days in May, 1921. Since then she has had no treatment, and is apparently quite well, although Mr. Spahlinger doubted whether this case had obtained immunity with serum treatment only.

During my second visit I read a letter from the

relative of a child, who had been unconscious when the treatment was begun, and in which the treatment had been intensive as no improvement was manifest after two doses. In ten days the child was up and trying to walk. I have no knowledge that this was a case of meningitis.

Types of Cases.—It will be seen by the foregoing hat the cases covered skin, gland, bone, lung and kidney infection, and judging from the cases I saw or heard about I consider there is a great deal of clinical evidence in favour of the treatment, as many of the cases had been given up as hopeless by their doctors, or by the sanatoria, and yet recovered and returned to work, some having remained well for seven years.

Mr. Spahlinger is trying to get some statistics as to the results of his treatment, and all his replies up to the time of my last visit were favourable. The results are certainly striking, and everything should be done to prove or disprove the efficacy of the treatment. Sir James Allen has interested himself in the matter, and is endeavouring to obtain some supplies for New Zealand.

I was much struck with the gratitude of all the patients, and with their readiness to come and be examined, or do anything to further the dissemination of any information that would be of benefit to Mr. Spahlinger and his treatment.

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