

Barriers to eye donation in Aotearoa New Zealand: a novel qualitative analysis

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ABSTRACT

AIM: Aotearoa New Zealand has experienced declining eye donation rates despite high levels of corneal disease and strong capacity to perform corneal transplantation. Demand for donor corneal tissue far exceeds supply. This study explored public attitudes toward eye donation, which have not previously been evaluated in New Zealand.

METHOD: Ten semi-structured focus groups were conducted, recorded and transcribed. Participant opinions were analysed using saturation and sentiment approaches. Transcripts were manually coded in NVivo15, with iterative thematic analysis until saturation was achieved.

RESULTS: A total of 44 participants were interviewed. Overall sentiment toward eye donation was positive, with 40 (90%) supporting donation for themselves or family. Barriers to donation included poor awareness (42, 96%), cultural considerations (41, 93%), feelings of disgust (23, 52%) and religious beliefs (13, 30%). Among Māori and Pacific participants (16, 44%), the absence of established tikanga (customary values/practices) around eye donation emerged as a key theme. Baseline knowledge was low: only 13 (30%) had prior awareness, and just two (5%) understood New Zealand's donation infrastructure.

CONCLUSION: Most focus group participants supported eye donation; however, poor awareness, cultural uncertainty and limited infrastructure remain barriers. New Zealand has the population and capacity to achieve self-sufficiency, but system-level changes are needed to improve eye donation rates.

Aotearoa New Zealand is a multicultural country of over 5 million people, with approximately 320 corneal transplants per year.¹ There is a high burden of end-stage keratoconus, which can often only be managed by corneal transplantation.² However, the rates of eye donation in New Zealand currently do not meet this demand. Since the COVID-19 pandemic in 2020, over half of all corneas used in New Zealand are imported. Rates of eye donation are decreasing over time.³ Significant ethnic differences were also noted among eye donors.³ The factors contributing to low eye donation rates in New Zealand remain largely unexplored.

In order to gain insight into these low eye donation rates, focus groups were conducted to ascertain public opinions and unearth hesitations, concerns or misconceptions surrounding eye donation in New Zealand. A qualitative empirical approach was applied, as this subject has not previously been investigated. Through individual quotations, insights and explorations of personal cultural factors, this study provides a basis for ongoing knowledge growth in this area.

Methods

Ethics approval was obtained through the Auckland Health Research Ethics Committee (AH26466). Participant informed written consent was obtained prior to the focus groups and audio recording.

With no prior examination of these themes, a semi-structured focus group framework consisting of 10 questions was designed to guide conversations. Participants were purposively recruited from a wide variety of sources to gain perspectives from those of varying ages, ethnicities and education levels, with the only inclusion criteria being that participants were over 18 and willing and able to consent to a focus group. Health professionals, including donor link nurses around New Zealand engaged in the eye-donation space, were approached via email. All other participants were approached in person via mutual connection, teaching roles or site visits. The principal investigator (NA) visited The University of Auckland Faculty of Medical and Health Sciences, Radio Lollipop children's charity

and Mercy Hospice Remuera to recruit participants.

Focus groups began in March 2024 and concluded in December 2024. Three focus groups occurred via Zoom video conferencing (Zoom Communications, United States of America), and the other seven occurred in person at a location of convenience for the participants. These locations were either private homes, public hospitals or Mercy Hospice (Ponsonby, Auckland). Prior to the commencement of the focus group, participants were asked about their understanding of eye donation, and a brief introductory description was provided if requested. There was no time limit for focus group discussions. Transcription was performed using the Microsoft Word 365 Transcription Tool, and manual corrections were performed. If recordings were low quality, challenging to understand or contained large numbers of te reo Māori words, the recordings were manually transcribed. Transcripts were transcribed verbatim, excluding “stop” words or sounds used as fillers (um, hmm, yeah, like). Transcripts were uploaded to Nvivo 15 QSR, and sections of text were manually coded into key themes and sub-themes related to the research questions. Sentiment analysis is the coding and automatic detection of language into positive, negative or neutral. This sentiment analysis allows for cross-examination, as well as an established hierarchy and patterns of ideas to develop. Saturation analysis is a qualitative technique by which data are continually collected until no new ideas or themes emerge. The saturation method of analysis was selected as this was a previously unexamined area with no established *a priori* saturation threshold; however, different themes reached saturation at different times, and therefore the planned number of 10 focus groups were completed.

Results

The participants were recruited throughout the study period, with 44 participants across 10 focus groups. The number of participants per group ranged from two to eight, with a mean of 4.2 ± 1.8 . The demographic information of the participants is demonstrated in Table 1. The majority of the participants were female members of the public aged between 30 and 64, but there was a wide variety of demographics. The youngest participant was 18 and the oldest was 84. “Patient” was used as a collective term for both patients with eye conditions and palliative care patients. The “Health professional” category included ophthal-

mology doctors (n=2), non-ophthalmology doctors (n=2), donor link nurses (n=3) and eye bank staff (n=1). “Public” was used when an individual had no ties to healthcare.

Several key themes were addressed in each focus group by multiple participants relating to the key research question of “*Why don’t New Zealanders donate their eyes?*”. The broad themes that emerged are outlined in Figure 1. Initially, the most notable theme was the lack of awareness around eye donation. There was almost no awareness of eye donation among the general public, and even among health professionals there was a limited understanding of the process, eligibility criteria or New Zealand’s high demand for corneal tissue. Discussion with family members around donation preference was uncommon, even among health professionals working in an eye donation field, such as donor link nurses. Those who had talked about eye donation with their family often did so in the context of older relatives expressing mistrust or reluctance to become organ donors.

“My uncle had to have an autopsy, and when we got the body back, there were cuts and things, and everyone was really unhappy. People thought they sold his organs.” –
24-year-old Male Samoan Public

Awareness of eye donation

Initial questioning about eye donation revealed a limited awareness of the topic. All health professionals were aware of eye donation, but only those working in ophthalmology had knowledge of the inclusion criteria or reasons behind eye donation. Healthcare students had an awareness comparable to the public. The only public members aware of eye donation were those with family members who were donors or acquaintances with someone diagnosed with keratoconus. The only patient aware of eye donation was an individual with formally diagnosed keratoconus. There was a widespread awareness of general organ donation but not specifically eye donation. Total awareness of organ donation and eye donation were 100.0% (n=44) and 31.8% (n=14), respectively. Eye donation awareness was only 8.7% (n=2) among the public. Five participants were aware of the high clinical need for eye donation in New Zealand due to the prevalence of keratoconus. However, only two participants were aware of the low rates of eye donation within New Zealand, and both were

Table 1: Demographics of focus group participants (total 44).

Gender	
Female	31 (70%)
Male	13 (30%)
Ethnicity	
NZ European	14 (32%)
Māori	10 (23%)
Pacific peoples	6 (14%)
Asian	4 (9%)
Affiliation	
Public	23 (52%)
Health professional	9 (20%)
Patient	7 (16%)
Healthcare student	5 (11%)
Age Group	
18–29	11 (25%)
30–64	28 (64%)
65+	5 (11%)

donation co-ordinators.

“I know that it is important for corneal transplants.” – 24-year-old Male Samoan Public

“The only reason I’ve heard about it is that my uncle donated his eyes when he died of a brain aneurysm.” – 27-year-old Female Māori Public

“The Pacific community has a lot of keratoconus, which is often advanced and requires corneal transplantation.” – 27-year-old Male Tongan Non-ophthalmology doctor

Perception of eye donation

The concept of eye donation was viewed positively by the majority of participants (90.9% [n=40]). Most participants recognised the need for eye donation and supported those with visual impairment having a second chance at sight. Participants who viewed eye donation negatively

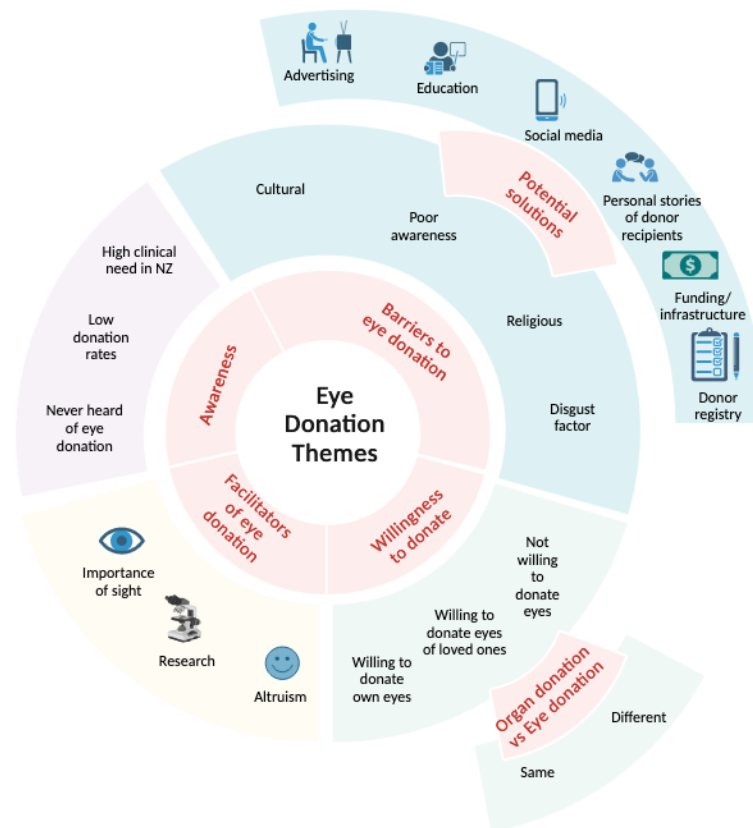
were in the minority (n=4). These participants raised strong objections to eye donation as a concept, expressing primarily cultural concerns. These concerns were further explored in a sub-theme around barriers to eye donation.

“It’s good to help people who cannot see.” – 73-year-old Female NZ European Patient

“Nah, feels like you are defiling them. I don’t agree with it.” – 71-year-old Male Māori Patient

“Because I’m Māori, I feel like my whānau [family] definitely would not like it. It just seems wrong somehow. It’s ‘Ko Te Whakatikenga’ [our vision]. It’s how we see our ancestors and ourselves. It’s more than just a body part for us. I think you would need some Māori elders or something to get on board and say this is all good; otherwise, you are never going to get any Māori donating.” – 30-year-old Male Māori Public

Figure 1: Key themes and sub-themes emerging from the focus groups. Major themes/focus areas of questioning are highlighted in red. The yellow sub-theme refers to the facilitators of eye donation suggested by participants. The blue sub-theme relates to reasons why New Zealand has low eye donation rates and potential solutions. The pink sub-theme relates to the participants' awareness of various aspects of eye donation. The green sub-theme relates to eye donation intentions.



Facilitators of eye donation

The reasons for supporting donation were similar across all the focus groups. Eye donation was frequently perceived as an altruistic and moral decision. A specific emphasis was placed by several NZ European females on the lack of necessity for body tissue once deceased. This perspective was not shared by the majority of the cohort.

“Because by the time they’re harvesting, generally, we should be dead. So we won’t care! It’s a nice thing to do.” – 44-year-old Female NZ European Public

The use of eye tissue for research purposes was also discussed by several non-medical participants

(n=3). It was not referenced by any health professionals. The primary sub-theme highlighted the importance and value of eyesight. Many (n=34) participants explicitly emphasised how personally significant vision is to them. Non-medical participants frequently referenced eyesight in connection with the other physical senses. Health professionals linked eyesight with quality of life indicators (QALYs) and discussed the socio-economic burden of visual impairment on health systems. Patients spoke of independence and said that good eyesight enables them to engage in activities of daily living and to engage socially with family, friends and acquaintances.

“Yeah, like you could lose your taste or your smell or your hearing, and life would go on, but I feel like you need

your sight to live.” – 23-year-old Male
NZ European Healthcare student

“Without sight, I would need to go into care, and I couldn’t care for my grandchildren. That would be a real shame.” – 73-year-old
Female NZ European Patient

Barriers to eye donation

Variable approaches were utilised to elicit discussions related to eye donation barriers. If focus group participants expressed discomfort with the concept of eye donation, they were asked to elaborate. If all participants were favourable to eye donation, they were asked to consider potential reasons for the low rate of eye donation in New Zealand. These four predominant categories included lack of awareness (n=42, 95.5%), cultural factors (n=41, 93.2%), disgust (n=23, 52.3%) and religious beliefs (n=13, 29.5%).

The influence of culture and religion on eye donation preferences were frequently discussed together, with considerable overlap across many sub-themes. The connections between culture, religion and spirituality are outlined visually in Figure 2. Māori and Pacific peoples made substantial contributions to this theme, offering both overlapping and distinct perspectives. Several cultural barriers were identified. First was the lack of established tikanga/customary practices surrounding eye donation: *“There is no uniform belief amongst Whānau Māori [Māori people]”* or Pacific peoples. The second barrier surrounded the *“tapu [sacred] nature of death and the tinana [body] itself.”* While there are diverse mortuary practices within Pacific and Māori communities, the sacred nature with which the body is viewed may often impose strict protocols for the handling of deceased individuals immediately after death.⁴ Such protocols may include restrictions in the handling of a deceased body by immediate whānau (family) only. Thirdly, Māori and Pacific participants discussed the impact of strong family connections and age-based hierarchy as potential barriers to eye donation. Many Māori and Pacific participants experienced strong cultural traditions encouraging respect for their elders, who are often seen as the keepers of wisdom, tradition and authority.⁵ Some expressed difficulty with accepting the concept of eye donation if their elders disagreed with it. Those who were open to it found it difficult to respectfully challenge their

elders’ decisions or perspectives in ways that did not diminish their mana (authority)—a paramount value within Māori and Pacific cultures.

“They won’t listen to us young ones. If you want to change things, you have to start from the top [of the family].”
– 24-year-old Male Samoan Public

“Our eyes are our vision; they help guide the way in the afterlife. Why would I give those away?” –
71-year-old Male Māori Patient

“Tapu is a huge concept in Tongan culture. When someone dies, their body is considered sacred. Interfering with a body is considered to be a huge disrespect to the deceased.” –
25-year-old Male Tongan Public

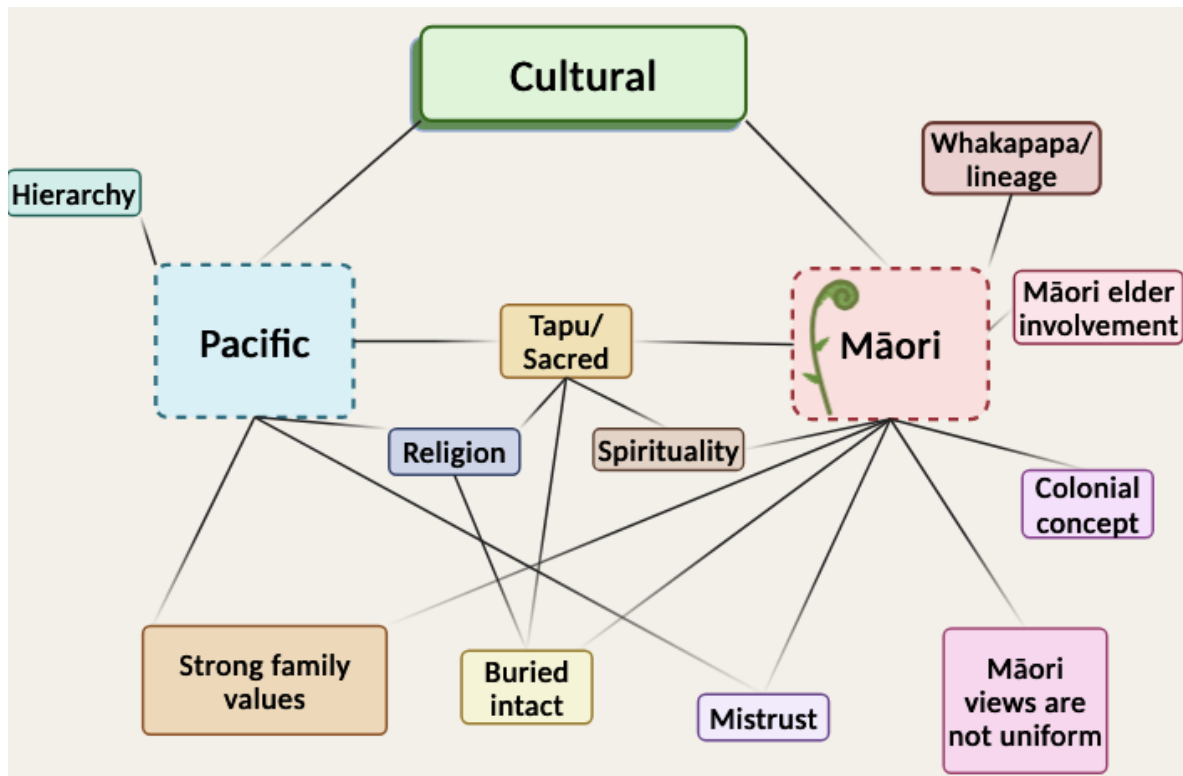
Several participants expressed a particular revulsion towards eye donation, more pronounced than organ donation. Over half of the participants used words or phrases to articulate this feeling, as depicted in Figure 3. The thought of eye donation elicited a strong, visceral revulsion, which affected all participants regardless of background. Some participants found eye donation repulsive because, unlike other organs, eyes are the focal point of gaze during conversation, deeply tied to a person’s spirituality and, for many, serve as a defining feature of their individuality.

Religious beliefs were, for some, a barrier to eye donation. Several participants referenced Catholicism and their perceived “rules” around burial. These concerns were entwined with the aforementioned cultural practices.

“Lots of Pacific peoples are very religious, and you know the church, I think, has only just allowed cremation. Traditionally, you had to be buried. Same with donation, I think.” –
34-year-old Female Samoan Public

The most ubiquitous barrier to eye donation elicited was the lack of public awareness. This was mentioned by nearly every participant (n=42). Participants generally recognised their limited understanding of the eye donation process. The health professionals felt there was a general lack of education at medical school on the eye donation process and indicated a paucity of publicised eye

Figure 2: Māori and Pacific cultural themes and their respective sub-theme connections visualised.



donation promotional material in healthcare facilities.

Willingness to donate

Almost all participants (n=40, 90.1%) agreed they would agree to an eye donation on behalf of a loved one who had passed away. Of these, 29 (65.9%) would agree to donate their loved one's eyes if the deceased explicitly expressed this wish prior to passing. Only nine participants (20.5%) had actively discussed their intent to donate organs with their families. Discussion around respecting the autonomy of the deceased was present in every focus group. Thirty participants expressed their desire to donate their own eyes, with the majority (n=22, 73.3%) affirming they would. Four participants were unsure, and four declined to donate their own eyes. Many participants discussed their driver licence and queried if this meant automatic organ donation at the time of death of all organs, including eyes. Several believed their driver licence organ donor status was tantamount to a donation registry.

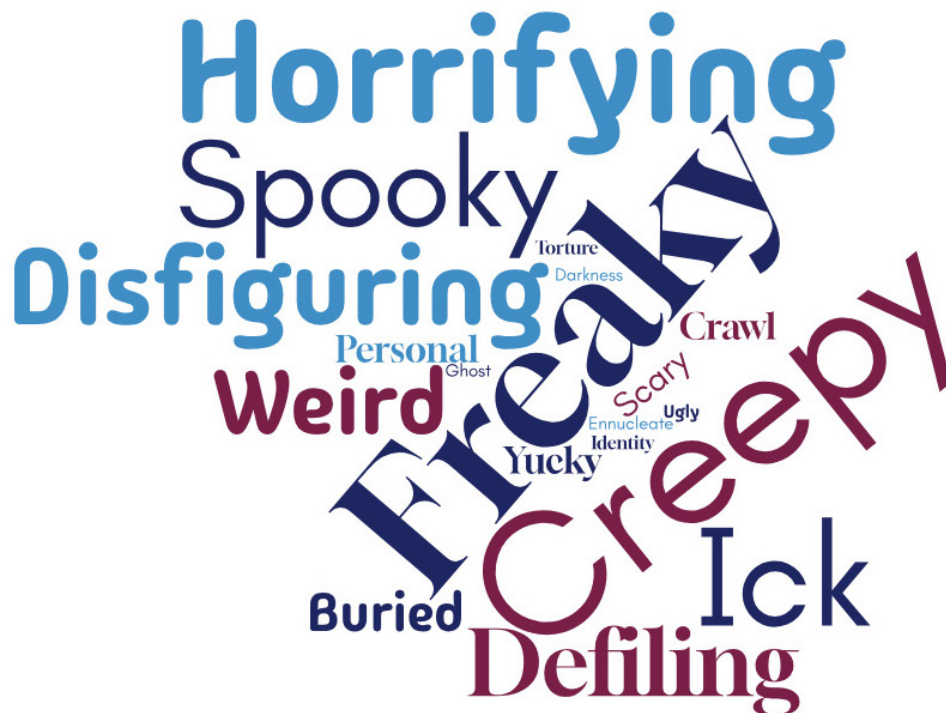
"I would 100% support any whānau who wanted to do it." – 27-year-old Female Māori Public

"I definitely want to donate. I have a donor on my licence, but I know when I die, it will be my family who decides." – 26-year-old Male Samoan Public

Potential solutions

Solutions to the eye donation deficit focussed on six areas: education (n=13, 29.5%), infrastructure and funding (n=13, 29.5%), advertising (n=10, 22.7%), personal stories from donor recipients (n=8, 18.2%), the establishment of a New Zealand donor registry (n=7, 15.9%) and social media (n=7, 15.9%). Having well-trained staff members *"who really know the science and understand my cultural perspective"* asking for consent was a recurring theme. Additionally, 90% (n=18) of those who commented thought that the person asking the question made a difference in whether or not someone would consent to eye donation.

Figure 3: Word frequency associated with discussion around the uncomfortable qualities associated with eyes.



"I definitely think that someone Tongan would be more convincing to a Tongan person." – 27-year-old Male Tongan Non-ophthalmology doctor

"Having a Māori face who can understand both worlds and is not being used by the system or tokenised by the system to advance donations is obviously a good thing." – 27-year-old Female Māori Public

After discussion surrounding poor public awareness, participants suggested increasing public visibility of eye donation via social media campaigns, printed advertisements, television campaigns and billboards.

Several participants emphasised that general education surrounding eye donation needs to be improved significantly. Suggested improvements included education campaigns targeting schools, rest homes and hospices. The role of the driver licence was discussed, and it was suggested that this be removed in favour of a formal donation registry. It was believed this would reduce confusion and allow greater objective evidence of a loved one's wishes for family members.

"Tell people they are going to have American corneas; people will hate that." – 45-year-old Female NZ European Public

"People should know that donor on your licence doesn't mean you're a donor aye." – 32-year-old Male Māori Public

"Where can I sign up to say I want to donate? Like if I want to donate my eyes, who do I tell?" – 23-year-old Female NZ European Public

The general underfunding and under-resourcing of public healthcare systems was discussed. The need for simpler donation pathway systems was frequently mentioned. An online screening tool for eligibility for eye donation was recommended. Many participants thought they were ineligible for eye donation because they had previously undergone an eye procedure, such as cataract surgery. Health professionals emphasised the need for an automatic referral system to facilitate easier access for staff and increase advertising to other clinicians. Two participants felt a specific eye donor nurse specialist would be helpful in

streamlining the donation process and increasing the number of donations.

“You need someone with a role that is funded, that has the time to go and meet with families, that has the experience.” – 52-year-old Female NZ European Donor link nurse

“I think Kiwis want to donate our eyes, but we just don’t have the systems in place to do it.” – 48-year-old Female Māori Donor link nurse

Sharing of personal stories from donor recipients was thought to be an emotive and powerful way to encourage donation. It normalised and humanised the process, which was described by patients as *“cold and clinical”*. This idea was particularly appealing to Māori, Pacific peoples and Asian participants. The Māori cultural value of whakapapa (lineage/genealogy) could be supported by hearing who will receive the tissue after donation. The breach of confidentiality was recognised and discussed, but participants felt even an anonymous acknowledgment from a donor-recipient would suffice.

“If they knew the whakapapa roughly ... where the tissue came from, I think that’s the way of showing aroha Manaaki [loving care] beyond the, you know, the veil.” – 27-year-old Female Māori Public

Discussion

The New Zealanders sampled in the focus groups generally perceived eye donation as a positive act, despite a significant lack of education surrounding the concept and donation process. The high number of participants who affirmed they would consent for themselves or their whānau to donate suggests New Zealand has the potential to be self-sufficient for eye tissue donation in order to meet domestic demand. Furthermore, there were no clear distinctions between gender, age or ethnicity; the response was uniformly positive. No particular group was more likely to have discussed their donation wishes, as this was consistently lacking across all demographics.

The general awareness of eye donation reported in this study is lower than other reported rates in the literature. An international systematic review of eye donation among the public found 30.8% of

participants had some knowledge of eye donation, compared with 8.7% of the public in this study.⁶ Low eye donation rates should be viewed in the context of limited awareness of eye donation and health literacy within New Zealand. There are well-established health inequities in New Zealand.^{7–9} Subsidised primary healthcare in New Zealand is limited, with primary care only partially subsidised in areas of high deprivation.^{10,11} Primary eye care funding is only available to a small number of eligible groups, such as children of low-income families. New Zealand has a relatively high rural population, resulting in significant geographical and financial barriers to accessing basic ophthalmic care.^{12,13} Healthcare access and health literacy are deeply interconnected, yet New Zealand lacks a designated health literacy policy, unlike countries such as Australia, Scotland and the United States of America.^{14,15}

The specific aversion to eye donation discussed in this study is established in the literature. Individuals are more likely to consent to solid organ donation than eye donation.^{16,17} An Australian survey found participants *“didn’t like the idea of someone cutting into their eyes”*. Many others were unable to adequately articulate a reason for their aversion to eye donation.¹⁷ A qualitative study in the United Kingdom suggested the predominant reason for family refusal of eye donation was concerns surrounding the physical appearance post-tissue removal.¹⁸ This was referenced as a significant barrier to eye donations for many individuals from different cultures in the focus groups.

A persistent theme throughout the study was the “donor” status on driver licences. There is no literature on the attitudes of New Zealanders toward eye donation or organ donation in general. Without a donor registry, it is challenging to estimate the number of New Zealanders who would intend to donate organs. A pseudo-registry exists from New Zealand driver licences, which contain “donor” information. Over the past 50 years, the number of individuals electing to become a “donor” on their driver licence is increasing.¹⁹ However, many participants lacked understanding regarding the non-legally binding nature of the driver licence organ donor declaration. In New Zealand, the decision to donate organs resides solely with the next of kin, irrespective of the “donor” status on a person’s driver license.¹⁹ All participants who mentioned their licence donor status were under the belief that it acts as a proxy donor registry and would be used at the time of

death to inform the decision respecting organ donation. This demonstrates the need to develop a clear donation pathway, including a registry, to improve eye donation uptake.

This study offered novel insights into the impact of culture on eye donation preference. A study of eye donation over the past decade in New Zealand found Māori and Pacific peoples were statistically less likely to donate their eyes compared to NZ Europeans.³ This study demonstrates that the reasons for Māori and Pacific peoples not donating their eyes are complex and culturally nuanced. In addition, Māori are disproportionately represented in areas of high socio-economic deprivation due to unequal power structures that fail to uphold Te Tiriti o Waitangi/the Treaty of Waitangi. The ongoing impacts of colonisation, including the systematic appropriation of Māori land and institutional racism within the healthcare system, have resulted in significant social, cultural, economic and health inequities. Similarly, many Pacific peoples who have migrated to New Zealand from the Pacific face considerable socio-economic disadvantage and poorer health outcomes than NZ Europeans, reflecting the lasting effects of complex colonial dynamics.^{7,20,21} For many Māori and Pacific peoples, the high levels of deprivation coupled with limited health resources frequently results in poorer health literacy.⁹ This worsens barriers to accessing healthcare and health outcomes for both these groups.^{7,8,22} Furthermore, both Māori and Pacific peoples have very high rates of keratoconus.^{7,23} The reasons behind these high rates are uncertain, but proposed theories include genetic and atopic associated pathology.² Keratoconus remains one of the leading indications for corneal transplantation in New Zealand,¹ and therefore, engaging this community in eye donation is paramount to improving access and outcomes. Māori and Pacific participants more frequently mentioned the role of the person asking about possible donation, and they were more likely to think this was important compared to other participants. This demonstrates the fundamental importance of a culturally safe eye donation process, as explored previously in the context of an Indigenous eye health framework.²⁴ If eye donation rates among Māori and Pacific peoples are to be improved, it will

require significant investment in the development of an individualised framework and protocol for eye donation for Māori and another for Pacific peoples. Any processes developed must prioritise cultural safety and respect, particularly when organ donation can be a sensitive cultural issue for many.

This study has several key limitations. As this is the first qualitative study of New Zealand donation attitudes, it is unclear if the saturation points reached in our study (between seven and nine focus groups) are replicable, and further semi-structured focus groups in this area may need to be conducted to confirm the various thematic saturation points. A wide variety of participants were recruited from various backgrounds, with a focus on key stakeholders in the area of eye donation. We recruited more females than males, which may influence the perspectives gathered due to the tendency of women to be more altruistic towards donation.²⁵ Our participants were also mostly based in urban centres, which may not reflect the views of rural New Zealand. Religious affiliation is a potentially relevant variable that was not recorded for the participants. The sample size is small, and more responses could have been collected from a survey. However, the quality and richness of information collected from focus groups were felt to be more appropriate to answering the research question.

Overall, the focus groups demonstrated favourable perspectives and views towards eye donation. Low donation rates are likely a combination of several factors, including poor public awareness, limited patient education, an unclear donation pathway and unique cultural perspectives on the sacred and revered nature of the body. Key areas identified to improve eye donation rates were patient and clinician education and donation infrastructure. Systemic changes, such as the development of a donation registry, might also lead to increasing eye donation numbers and therefore self-sufficiency in corneal graft supply. Additional engagement with Māori and Pacific people's cultural leaders is also required to further appreciate the complex intersections of eye donation with cultural attitudes.

COMPETING INTERESTS

This project was funded in part by the Health Research Council of New Zealand.

ACKNOWLEDGMENTS

We would like to acknowledge the participants for their valuable contribution to this research and the Health Research Council of New Zealand for supporting our work. We would also like to thank Mercy Hospice and Radio Lollipop charities.

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<https://nzmj.org.nz/journal/vol-139-no-1632/barriers-to-eye-donation-in-aotearoa-new-zealand-a-novel-qualitative-analysis>

CITATION

Allen N, Gokul A, Zhang J, et al. Barriers to eye donation in Aotearoa New Zealand: a novel qualitative analysis. *N Z Med J*. 2026 Mar 27;139(1632):71-81. doi: 10.26635/6965.7234

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