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

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ABSTRACT

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

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

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

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

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

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

Methods

A retrospective, register-based cross-sectional analysis of participants invited to diabetic retinal screening in Te Tai Tokerau between 31 May 2011 and 17 June 2020 was performed. All individuals invited to attend for screening in Te Tai Tokerau

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

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

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

Results

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

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

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

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

Discussion

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

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

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

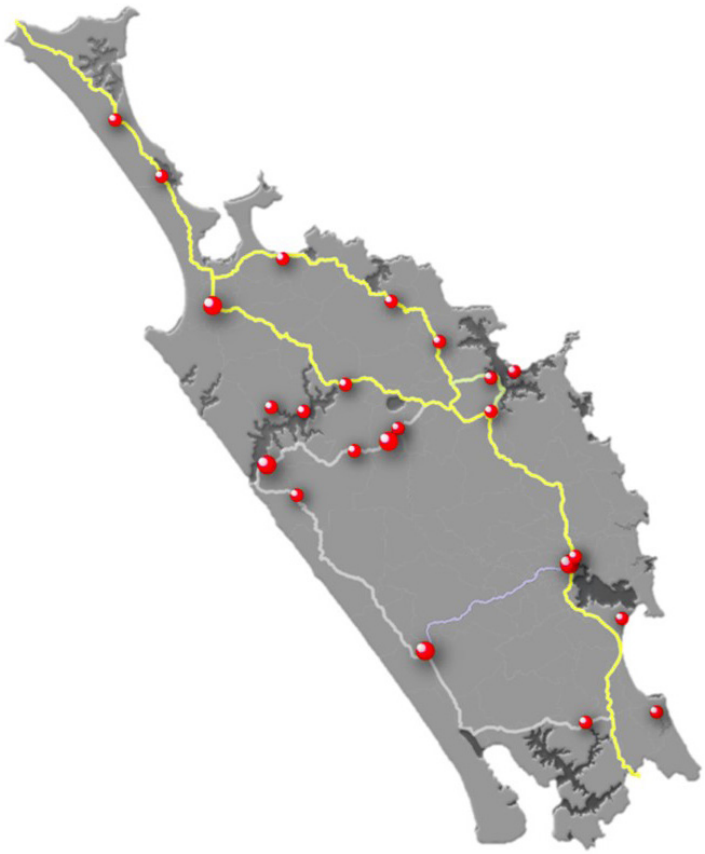

Table 1: Baseline distribution of people with diabetes in Te Tai Tokerau invited to attend retinal screening, May 2011–June 2020.

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

*Significant p-values from Chi-squared tests.

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

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

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

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

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

In accordance with previous studies from overseas,[11–14,19] this study found socio-economic deprivation to be associated with non-attendance at diabetic retinal screening. A large multicentre study of patients (n=79,775) with diabetic retinopathy referred to secondary care in the UK demonstrated that socio-economic deprivation was associated with late presentation of diabetic

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

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

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

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

COMPETING INTERESTS
Nil.

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