Interrupted diabetes eye care in Te Toka Tumai Auckland 2008–2019: analysis of routinely collected health-facility data

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ABSTRACT

AIM: The aim of this study was to quantify interrupted care (delayed care and complete loss to follow-up) across the diabetes eye care pathway among people aged ≥15 years in Auckland, New Zealand, and assess disparities by age, sex, ethnicity, deprivation and diabetes duration.

METHOD: We analysed data from people engaged with diabetes retinal screening in Auckland between 1 January 2008 and 31 December 2019. Follow-up continued from first appointment until death or study end. Delayed care and complete loss to follow-up were assessed at retinal screening, when referred from screening to ophthalmology with referrable diabetic retinopathy (R3 or worse), and at ophthalmology review.

RESULTS: Almost one-third of people experienced delays in retinal screening care beyond 24 months (n=4,471/14,708; 30.4%) and one-fifth were completely lost to follow-up (n=2,970/14,708; 20.2%). Similar proportions were observed for a delay beyond 6 months when referred from retinal screening to ophthalmology with referrable retinopathy (n=648/1,909; 33.9%) and a delay beyond 12 months between ophthalmology review (n=366/1,136; 32.2%) or complete loss to follow-up from these two stages (n=433/1,909; 22.7% and n=188/1,136; 16.5% respectively). Younger adults were more likely to experience complete loss to follow-up from retinal screening and ophthalmology review compared to people aged 50–59 years; compared to NZ Europeans, all other ethnicity groups were more likely to be lost to follow-up from retinal screening, with Māori and Pacific peoples experiencing the greatest disparity.

CONCLUSION: Loss to follow-up and delayed care were common across all stages of the diabetes care pathway assessed, with disparities by age and ethnicity.

Diabetic retinopathy is a leading cause of preventable vision impairment in the working-age population.[1] Optimal management of blood glucose, cholesterol and blood pressure, and avoiding smoking, help to reduce the risk of development or progression of retinopathy.[2,3] If significant disease develops, timely ocular treatment with laser or anti-vascular endothelial growth factor (anti-VEGF) injections is crucial to prevent vision loss.[4]

As symptomatic vision loss due to diabetic retinopathy manifests in the very late stages of the disease, regular retinal screening is necessary to ensure early detection and timely treatment.[5] The World Health Organization (WHO) recommends that screening should occur every 1–2 years.[6] Ideally, the screening interval would be personalised and take into account the various risk factors present for progression of diabetic retinopathy for each individual.[7] However, for pragmatic reasons, the retinal screening interval is often fixed or based on the retinal grade.

In 2022, Aotearoa New Zealand's (hereafter New Zealand) Ministry of Health – Manatū Hauora estimated that 307,400 people had diabetes (43.1 per 1,000 population).[8] The retinal screening guidance in New Zealand (Appendix 1) recommends that people with no or minimal retinopathy (grade R0 and R1) attend retinal screening every 2 years (type 1) or 2–3 years (type 2).[9] If a person develops a threshold severity of retinopathy (R3 and above), they are referred from retinal screening to an ophthalmology clinic for closer monitoring and treatment, and attendance at this appointment should generally occur within 6 months.[9] Some people whose diabetic maculopathy has stabilised after treatment can be referred back to retinal screening. However, many will need to stay under the care of ophthalmologists, who then decide the follow-up frequency depending on the severity of

the disease and the underlying risk factors such as blood glucose level and hypertension.[9]

Each time a patient experiences interrupted care across the diabetes eye care pathway, an opportunity to prevent vision loss might be missed. We recently reported that between 2006 and 2019, only two-thirds of people with diabetes in New Zealand had engaged with diabetes eye care (retinal screening or an eye clinic) at least once every 2 years.[10] This estimate was based on the analysis of administrative data without information on where on the pathway people became disconnected from care.

In this analysis, we address the knowledge gap observed in our previous work by using more detailed facility-based clinical data in Te Toka Tumai Auckland (previously Auckland District Health Board).[11] This study aimed to 1) summarise loss to follow-up through the diabetes eye care pathway among people aged ≥15 years in the Auckland Region and 2) identify disparities across population sub-groups by age, sex, ethnicity, area-level deprivation and duration of diabetes.

Method

2.1 Ethical approval and reporting

Ethical approval for this study was obtained from the Health and Disability Ethics Committee (ref: 21/NTB/97), and locality approval was obtained from Te Toka Tumai Auckland (ref: A+9307). We have reported the study in accordance with the RECORD statement (REporting of studies Conducted using Observational Routinely-collected Data, Appendix 2).[12]

2.2 Study design and setting

This is a retrospective cohort study. During the period the data were collected (and before the health sector reforms that commenced in July 2022), Te Toka Tumai Auckland was one of 20 district health boards across the country and was responsible for delivering healthcare services to the approximately half a million people living in and around central Auckland.[13]

2.3 Participants

The study population was identified from the diabetes retinal screening database of Te Toka Tumai Auckland and consisted of people with diabetes residing in Auckland who attended at least one retinal screening appointment at Te Toka Tumai Auckland between 1 January 2008 and 31 December 2019 (inclusive) at which time they were aged 15 years or above. The individuals were followed from the date of the first screening event until death or the study end date (31 December 2019); all events related to retinal screening or diabetes-related ophthalmology visits were analysed.

2.4 Data sources

The cohort was established from the Diabetes Retinal Screening Service dataset of Te Toka Tumai Auckland (held on a bespoke database "HCC" that serves the diabetes service). From this dataset, we received demographic data of individuals (age, sex, ethnicity and area-level deprivation) and clinical information related to each retinal screening event attended, such as the duration and type of diabetes and retinopathy grades.

The National Health Index (a unique identifier of the individuals) was used to link data from additional sources. Data related to the engagement of individuals with ophthalmology services were obtained from the National Non-Admitted Patient Collection (NNPAC) dataset held by the Ministry of Health – Manatū Hauora (Purchase Unit codes; S40002 = first attendance; S40003 = subsequent attendance).[14]

Similarly, the mortality collection dataset[15] was used to obtain the date of death data of all individuals who died during the study period. We sought missing retinopathy grades from the Te Toka Tumai Auckland clinical database, which houses patient records and letters (n=549 individuals had at least one missing retinopathy grade and linkage identified a grade for 502 of these [91.4%]).

2.5 Study variables

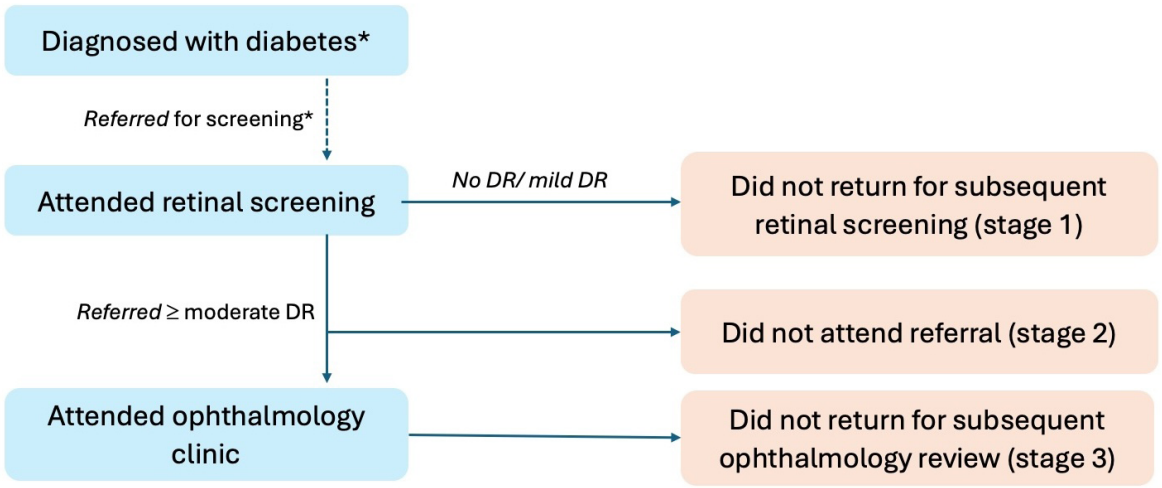
Outcome variables

The primary outcome was the interrupted care status at each stage of the diabetes eye care pathway (Figure 1), with each eligible person being categorised as one of:

1. *complete loss to follow-up*, when an individual never attended the expected next event;
2. *delayed care*, when an individual attended the expected next event, but not within the expected time frame; or
3. *no interrupted care*, when an individual attended all expected next events within the expected timeframe.

This status is reported as a proportion of the

Figure 1: Stages of the diabetes eye care pathway and corresponding points of potential interrupted care.



*Data on the population diagnosed with diabetes were unavailable to assess attendance at retinal screening following diabetes diagnosis.
DR = diabetic retinopathy.

eligible population at each stage of the diabetes eye care pathway, from retinal screening (stage 1), when referred from screening to ophthalmology (stage 2) and from ophthalmology review (stage 3). Details of the definition (and calculation) of the eligible denominator population, follow-up period and numerator population are provided in Appendix 3.

Explanatory variables

The explanatory variables were: *age* (categorised as 15–29, 30–39, 40–49, 50–59, 60–69, 70–79, 80+ years); *sex* (female, male or unspecified); *prioritised ethnicity*, whereby people are assigned to one ethnic group regardless of how many groups they report belonging to (categorised as Māori, Pacific, Asian, NZ European or Other)[16]; *area-level deprivation* (based on NZDep13[17] mapped from the domicile code on the National Health Index) arranged into quintiles from least (Q1) to most (Q5) deprived; and *diabetes type* (type 1, type 2 or Other).

2.6 Data processing and analysis

We calculated the expected number of events for each individual (follow-up duration divided by the recommended screening intervals of 24 months for retinal screening, 6 months for referral attendance and 12 months for ophthalmology review) and identified the individuals who experienced 1) complete loss to follow-up, 2) delayed care and 3) no interrupted care at each of the three stages in the pathway (Figure 1). For people with delayed care, the proportion of all expected appointments that were attended was also calculated.

Our use of the 24-month cutoff for retinal screening interval and the 6-month cutoff for referral attendance interval was based on Ministry of Health – Manatū Hauora guidance,[9] while the 12-month cutoff for ophthalmology review was informed by the modest (generic) follow-up interval practised in Te Toka Tumai Auckland (where co-author DS practiced).

Descriptive statistics were reported for patient characteristics. Counts and percentages were used for categorical data, and numerical data were summarised in terms of median and interquartile range (IQR). The relationship between the outcome variable at each stage of the care pathway and the explanatory variables was analysed for disparities across population sub-groups by age, sex, ethnicity and area-level deprivation quintile using log-binomial regression, controlling for relevant confounders. To explore if there were distinct patterns between people accessing services (fully or partially) and those not accessing services, we ran two models dichotomising the outcome variable as 1) "complete loss to follow-up" (Y=1) versus "no interrupted care or delayed care" (Y=0) and 2) "delayed care" (Y=1) versus "no interrupted care" (Y=0).

We did not include the "diabetes type" variable in the models since 95% of participants had type 2 diabetes, and the models did not converge with this variable. People with missing ethnicity data (n=32) were also excluded from the models. The decision of the model fit was informed by a dispersion statistic value closer to one (not over- or under-dispersed estimates). The direction and strength of association were estimated in terms of relative risks (RR) and their 95% confidence intervals (CIs). All tests were two-sided with a 5% significance level. All analyses were conducted in R 4.5.0 (R Core Team, 2024, R Foundation for Statistical Computing).

We conducted a sensitivity analysis for loss to follow-up estimates for retinal screening and ophthalmology by adding 2 months to the 24- and 12-month follow-up periods, respectively, to allow for scheduling or rescheduling of appointments around the due date, according to the Ministry of Health – Manatū Hauora guidelines.[9]

Results

We received de-identified retinal screening records for 21,617 people who attended diabetes retinal screening at Te Toka Tumai Auckland during the study period (1 January 2008 to 31 December 2019). We removed records of residents outside of Te Toka Tumai Auckland at the time of their appointment (n=3,240) as well as records provided erroneously (five people aged <15 years at their first appointment and five women with gestational diabetes). Of the remaining 18,367 people, 47 with missing retinopathy grades at their first appointment were excluded, leaving 18,320 people for analysis (study population selection shown in Appendix 4). After removing people ineligible for analysis at each stage of the pathway due to death or an insufficient follow-up period, there were 14,708 people eligible for analysis from retinal screening, 1,909 for their referral appointment and 1,136 for ophthalmology review (Appendix 4). At the retinal screening stage, eligible people had a median (IQR) of 7.4 (4.8–9.9) years of follow-up between their first engagement with screening and the study end date (or their death); people engaged with ophthalmology had a median (IQR) of 6.1 (3.4–8.5) years of follow-up.

Half of the 14,708 individuals eligible for analysis for retinal screening (stage 1) attended retinal screening events at least once every 24 months during the follow-up period and therefore had no interrupted care (n=7,267; 49.4%). A further 30.4% of participants (n=4,471) experienced delayed care, while one in five individuals were completely lost to follow-up (n=2,970; 20.2%) (Table 1). The median proportion of retinal screening events attended by those with delayed care during the study period was 50.0% (IQR 40.0–66.7%). The proportion of people attending all expected retinal screening events reduced as the period of follow-up (and therefore number of expected events) increased, from 73.1% (1,921/2,627) for people with two expected events down to 29.6% (1,011/3,421) for people with six expected events (Appendix 6).

Sensitivity analysis showed that extending the follow-up period by 2 months moved 589 individuals from delayed care to no interrupted care at retinal screening, increasing the proportion of eligible individuals experiencing no interrupted care from 49.4% to 53.4% (4.0 percentage-point increase).

The corresponding increase of people experiencing no interrupted care at referral and ophthalmology review was 3.7 and 7.0 percentage-points respectively (Appendix 5).

The likelihood of complete loss to follow-up from retinal screening was significantly higher among adults aged 30–39 years (RR=1.46; 95% CI 1.13–1.89) and 40–49 years (RR=1.32; 95% CI 1.11–1.58) compared with those aged 50–59 years, and among all ethnicity groups compared with NZ Europeans, being greatest for Māori (RR=1.46; 95% CI 1.26–1.70) and Pacific peoples (RR=1.45; 95% CI 1.28–1.65). There was a gradient of increasing likelihood of complete loss to follow-up with increasing area-level deprivation (Table 2).

The likelihood of delayed care from retinal screening showed a similar pattern across ethnicity groups and area-level deprivation but differed across age groups, with younger age groups being less likely than those aged 50–59 years to have delayed care (Table 2).

When referred to ophthalmology from retinal screening, 43.3% (n=828/1,909) of the eligible individuals attended within 6 months. A further 648 people (34.0%) attended at some time after 6 months, while 433 (22.7%) never reached ophthalmology (Table 1). Of those reaching ophthalmology (n=1,476), the median time between screening and review was 5.1 months (IQR 3.0–12.5 months; range 4 days to 123 months). Almost one-fifth of people reaching ophthalmology (n=268; 18.1%) did so between 6 and 12 months after referral, while one-quarter (n=380; 25.7%) attended after more than 12 months (Appendix 6). There were

no significant differences in the likelihood of complete loss to follow-up versus no interrupted care/delayed care during referral across the population groups. However, among the group who experienced delayed care during referral, men were 16% less likely than women to attend their referral within 6 months (RR=0.84; 95% CI 0.75–0.95), and Asian people were 19% less likely than NZ Europeans to attend within that time frame (RR=0.81; 95% CI 0.69–0.95) (Table 3).

Among the 1,136 individuals eligible for analysis at ophthalmology review, one in six (n=188; 16.6%) experienced complete loss to follow-up, while approximately one-third (n=366; 32.2%) experienced delayed care and one-half (n=582; 51.2%) attended all expected ophthalmology reviews (at least once every 12 months). Of those with delayed care, the median proportion of the expected annual ophthalmology reviews attended was 56.3% (IQR 40.0–75.0%). The proportion of people attending all expected ophthalmology review events was highest for people with two expected events (70.2%; 85/121) and thereafter varied between 42.5% and 57.1% for up to 11 expected events (Appendix 6).

Similar to the result seen for retinal screening, people aged <40 years and 40–49 years were more likely to experience complete loss to follow-up from ophthalmology review compared with individuals aged 50–59 years. In contrast to retinal screening, Pacific peoples were less likely to experience complete loss to follow-up compared with NZ Europeans; there were no other significant differences across population groups for complete loss to follow-up or delayed care (Table 4).

Discussion

We analysed individual-level clinical data of people with diabetes aged ≥15 years in Auckland, New Zealand, from 2008 to 2019, and found that at each stage of the diabetes eye care pathway (screening; referral to ophthalmology; subsequent ophthalmology care) approximately half of individuals attended appointments within the recommended time interval, one-third experienced delayed care and one in five were completely lost to follow-up. For retinal screening, complete loss to follow-up was higher for Māori and Pacific peoples versus NZ Europeans, younger versus older age groups and people living in more versus less deprived areas. For referral and subsequent ophthalmology clinic care, differences between population groups were less evident.

Our results are broadly consistent with other studies in New Zealand, though there is heterogeneity in how findings are reported.[18–20] This includes our previous study that used national Ministry of Health – Manatū Hauora data and found that between 2006 and 2018, among people with a median of 5.5 years of follow-up, 62% attended retinal screening at least every 2 years.[10] While the analysis reported here has used robust, routinely collected data from Te Toka Tumai Auckland, the lower result is likely due to the inability to monitor the engagement with diabetes eye care of people who have moved outside the region.

This inability to link with data from other regions highlights the need to monitor eye care data at a national rather than regional level. A situational analysis of eye care in 2022 concluded that the health information system needed major strengthening to enable effective monitoring of eye health.[21] For diabetes eye care, in addition to strengthening data infrastructure and analytical capacity, monitoring efforts will be bolstered when a national diabetes register replaces our virtual register[22,23] to provide a complete list of everyone in need of regular eye health services (either retinal screening or ophthalmology).

A further enhancement of the information system would see key clinical information recorded at each eye care event including risk factors such as most recent HbA_{1c},[24] retinopathy grade, visual acuity and management. These enhancements would enable assessment of the impact of interrupted care on patient outcomes such as progression of disease and avoidance of vision loss, as well as more readily enable individualised retinal screening intervals to provide more equitable and cost-effective care.[7] For example, if there was a record of referral from retinal screening to ophthalmology review in the datasets, we would not require the assumptions and data linkage undertaken for this analysis, and progress through the care pathway for people with maculopathy (which has a less distinct referral threshold than retinopathy[9]) in the absence of referrable retinopathy could also be assessed. A further example of the benefits of a robust information system is seen in the Danish context, where 5 years of follow-up data demonstrated each missed appointment by people enrolled in the retinal screening programme roughly doubled the risk of progression to severe disease.[25]

Table 1: Summary of interrupted diabetes eye care across the service pathway in Te Toka Tumai Auckland, 2008–2019.

Stages in the care pathway	Complete loss to follow-up*		Delayed care*		No interrupted care		Total	
	n (row %)	Follow-up duration^ Median (IQR) (years)	n (row %)	Follow-up duration^ Median (IQR) (years)	n (row %)	Follow-up duration^ Median (IQR) (years)	N	Follow-up duration^ Median (IQR) (years)
Retinal screening (stage 1)	2,970 (20.2)	7.6 (4.2–9.2)	4,471 (30.4)	9.8 (7.1–10.5)	7,267 (49.4)	6.1 (3.9–8.9)	14,708	7.4 (4.8–9.9)
Referral from retinal screening to ophthalmology review (stage 2)	433 (22.7)	4.9(2.5–8.5)	648 (34.0)	1.2 (0.7–2.4)	828 (43.3)	0.3 (0.2–0.4)	1,909	0.6 (0.3–2.5)
Ophthalmology review (stage 3)	188 (16.6)	3.6 (2.3–5.9)	366 (32.2)	7.5 (5.1–9.2)	582 (51.2)	5.8 (2.9–8.3)	1,136	6.1 (3.4–8.5)

*Complete loss to follow-up was when an individual never attended the expected next event; delayed care was when an individual attended the expected next event, but not within the expected time frame (24 months for retinal screening, 6 months for referral and 12 months for ophthalmology review).
^Follow-up duration refers to the median number of years participants at each pathway stage were followed in the analysis. For each participant, this was calculated as the time between the date of the first attended event and whichever occured first of the study end or the date of death.
IQR = interquartile range.

Table 2: Interrupted care from retinal screening in Te Toka Tumai Auckland, 2008–2019.

Characteristics		Eligible population N (col%)	Retinal screening status			Complete loss to follow-up vs no interrupted care/delayed care N=14,676^		Delayed care vs no interrupted care N=11,738^^	
			Complete loss to follow-up	Delayed care	No interrupted care	Relative risk (95% CI)	p-value‡	Relative risk (95% CI)	p-value‡
			N (row%)	N (row%)	N (row%)				
Total	-	14,708 (100.0)	2,970 (20.2)	4,471 (30.4)	7,267 (49.4)	-	-	-	-
Sex	Female	6,909 (47.0)	1,414 (20.5)	2,157 (31.2)	3,340 (48.3)	Ref	-	Ref	-
	Male	7,799 (53.0)	1,556 (20.0)	2,316 (29.7)	3,927 (50.4)	1.04 (0.96–1.13)	0.3181	0.98 (0.94–1.03)	0.4180
Age (years)	<30	184 (1.3)	43 (23.4)	45 (24.5)	96 (52.2)	1.24 (0.87–1.78)	0.2389	0.99 (0.78–1.27)	0.9583
	30–39	347 (2.4)	99 (28.5)	83 (23.9)	165 (47.6)	1.46 (1.13–1.89)	0.0040	0.94 (0.78–1.13)	0.4977
	40–49	920 (6.3)	253 (27.5)	210 (22.8)	457 (49.7)	1.32 (1.11–1.58)	0.0020	0.87 (0.77–0.99)	0.0363
	50–59	2,196 (14.9)	483 (22.0)	604 (27.5)	1,109 (50.5)	Ref	-	Ref	-
	60–69	3,657 (24.9)	692 (18.9)	1,131 (30.9)	1,834 (50.2)	0.84 (0.74–0.96)	0.0105	1.09 (1.01–1.17)	0.0353
	70–79	3,717 (25.3)	675 (18.2)	1,183 (31.8)	1,859 (50.0)	0.85 (0.74–0.97)	0.0153	1.16 (1.07–1.25)	0.0002
	80+	3,687 (25.1)	725 (19.7)	1,215 (33.0)	1,747 (47.4)	1.02 (0.89–1.16)	0.7943	1.27 (1.18–1.37)	0.0000
Ethnicity	NZ European	4,383 (29.8)	708 (16.2)	1,198 (27.3)	2,477 (56.5)	Ref	-	Ref	-
	Asian	5,315 (36.1)	1,005 (18.9)	1,645 (31)	2,665 (50.1)	1.16 (1.04–1.29)	0.0089	1.15 (1.09–1.23)	0.0000
	Māori	1,531 (10.4)	388 (25.3)	510 (33.3)	633 (41.3)	1.46 (1.26–1.70)	<0.001	1.24 (1.14–1.35)	<0.001
	Pacific peoples	2,764 (18.8)	706 (25.5)	906 (32.8)	1,152 (41.7)	1.45 (1.28–1.65)	<0.001	1.21 (1.13–1.30)	<0.001
	Other	683 (4.6)	143 (20.9)	204 (29.9)	336 (49.2)	1.26 (1.03–1.55)	0.0269	1.15 (1.02–1.30)	0.0181
	Missing	32 (0.2)	20 (62.5)	8 (25.0)	4 (12.5)	-	-	-	-

Table 2 (continued): Interrupted care from retinal screening in Te Toka Tumai Auckland, 2008–2019.

Characteristics		Eligible population N (col%)	Retinal screening status			Complete loss to follow-up vs no interrupted care/delayed care N=14,676^		Delayed care vs no interrupted care N=11,738^^	
			Complete loss to follow-up	Delayed care	No interrupted care	Relative risk (95% CI)	p-value‡	Relative risk (95% CI)	p-value‡
			N (row%)	N (row%)	N (row%)				
Area-level deprivation (quintiles)	1 (least deprived)	1,828 (12.4)	247 (13.5)	400 (21.9)	1,181 (64.6)	Ref	-	Ref	-
	2	3,054 (20.8)	494 (16.2)	858 (28.1)	1,702 (55.7)	1.18 (1.00–1.40)	0.0417	1.30 (1.18–1.44)	<0.001
	3	3,489 (23.7)	632 (18.1)	1,051 (30.1)	1,806 (51.8)	1.35 (1.15–1.58)	0.0003	1.43 (1.29–1.57)	<0.001
	4	2,161 (14.7)	477 (22.1)	731 (33.8)	953 (44.1)	1.65 (1.39–1.96)	<0.001	1.67 (1.51–1.85)	<0.001
	5 (most deprived)	4,176 (28.4)	1,120 (26.8)	1,431 (34.3)	1,625 (38.9)	2.04 (1.74–2.38)	<0.001	1.78 (1.62–1.96)	<0.001
Diabetes type*	Type 1	695 (4.7)	105 (15.1)	147 (21.2)	443 (63.7)	-	-	-	-
	Type 2	13,913 (94.6)	2,820 (20.3)	4,304 (30.9)	6,789 (48.8)	-	-	-	-
	Other	71 (0.5)	23 (32.4)	17 (23.9)	31 (43.7)	-	-	-	-
	Missing	29 (0.2)	22 (75.9)	3 (10.3)	4 (13.8)	-	-	-	-

*Diabetes type variable was not included in the regression models as there was no convergence.
^32 peoples' cases with missing ethnicity data were removed from the regression analysis.
^^12 peoples' cases with missing ethnicity data were removed from the regression analysis.
‡p-value derived from log-binomial regression model adjusted for age, sex, ethnicity and area-level deprivation, testing whether the relative risk differs from 1.
CI = confidence interval.

Table 3: Interrupted care when referred from retinal screening to ophthalmology in Te Toka Tumai Auckland, 2008–2019.

Characteristics		Eligible population N (col%)	Ophthalmology referral status			Complete loss to follow-up vs no interrupted care /delayed care N=1,908^		Delayed care vs no interrupted care N=1,476	
			Complete loss to follow-up	Delayed care	No interrupted care	Relative risk (95% CI)	p-value‡	Relative risk (95% CI)	p-value‡
			N (row%)	N (row%)	N (row%)				
Total	-	1,909 (100.0)	433 (22.7)	648 (33.9)	828 (43.4)	-	-	-	-
Sex	Female	827 (43.3)	190 (23.0)	311 (37.6)	326 (39.4)	Ref	-	Ref	-
	Male	1,082 (56.7)	243 (22.5)	337 (31.1)	502 (46.4)	0.98 (0.83–1.16)	0.8320	0.84 (0.75–0.95)	0.0041
Age (years)	<40*	97 (5.0)	28 (28.9)	27 (27.8)	42 (43.3)	1.26 (0.87–1.83)	0.2140	0.93 (0.67–1.29)	0.6795
	40–49	152 (8.0)	40 (26.3)	45 (29.6)	67 (44.1)	1.20 (0.86–1.67)	0.2780	0.97 (0.75–1.26)	0.8465
	50–59	370 (19.4)	80 (21.6)	120 (32.4)	170 (45.9)	Ref	-	Ref	-
	60–69	513 (26.9)	113 (22.0)	182 (35.5)	218 (42.5)	1.02 (0.79–1.32)	0.8560	1.11 (0.94–1.32)	0.2209
	70–79	449 (23.5)	90 (20.0)	162 (36.1)	197 (43.9)	0.91 (0.70–1.20)	0.5080	1.12 (0.93–1.33)	0.2242
	80+	328 (17.2)	82 (25.0)	112 (34.1)	134 (40.9)	1.12 (0.85–1.47)	0.4360	1.13 (0.93–1.37)	0.2256
Ethnicity	NZ European	499 (26.1)	126 (25.3)	166 (33.3)	207 (41.5)	Ref	-	Ref	-
	Asian	668 (35.0)	137 (20.5)	195 (29.2)	336 (50.3)	0.86 (0.69–1.07)	0.1780	0.81 (0.69–0.95)	0.0111
	Māori	177 (9.3)	43 (24.3)	65 (36.7)	69 (39.0)	1.05 (0.77–1.42)	0.7750	1.11 (0.90–1.37)	0.3449
	Pacific peoples	487 (25.5)	105 (21.6)	199 (40.9)	183 (37.6)	0.94 (0.74–1.20)	0.6140	1.13 (0.96–1.33)	0.1317
	Other	77 (4.0)	22 (28.6)	22 (28.6)	33 (42.9)	1.20 (0.81–1.77)	0.3600	0.90 (0.64–1.26)	0.5260
	Missing	1 (0.1)	-	1 (100.0)	-	-	-	-	-

Table 3 (continued): Interrupted care when referred from retinal screening to ophthalmology in Te Toka Tumai Auckland, 2008–2019.

Characteristics		Eligible population N (col%)	Ophthalmology referral status			Complete loss to follow-up vs no interrupted care /delayed care N=1,908^		Delayed care vs no interrupted care N=1,476	
			Complete loss to follow-up	Delayed care	No interrupted care	Relative risk (95% CI)	p-value‡	Relative risk (95% CI)	p-value‡
			N (row%)	N (row%)	N (row%)				
Area-level deprivation (quintiles)	1 (least deprived)	213 (11.2)	52 (24.4)	71 (33.3)	90 (42.3)	Ref	-	Ref	-
	2	383 (20.1)	103 (26.9)	117 (30.5)	163 (42.6)	1.10 (0.82–1.46)	0.5310	0.95 (0.76–1.18)	0.6282
	3	462 (24.2)	100 (21.6)	157 (34.0)	205 (44.4)	0.90 (0.67–1.21)	0.4920	0.98 (0.80–1.21)	0.8750
	4	284 (14.9)	60 (21.1)	102 (35.9)	122 (43.0)	0.87 (0.62–1.21)	0.4060	0.97 (0.77–1.22)	0.7903
	5 (most deprived)	567 (29.7)	118 (20.8)	201 (35.4)	248 (43.7)	0.85 (0.63–1.15)	0.2880	0.94 (0.76–1.16)	0.5658
Diabetes type*	Type 1	195 (10.2)	47 (24.1)	69 (35.4)	79 (40.5)	-	-	-	-
	Type 2	1,697 (88.9)	383 (22.6)	576 (33.9)	738 (43.5)	-	-	-	-
	Other	10 (0.5)	2 (20.0)	2 (20.0)	6 (60.0)	-	-	-	-
	Missing	7 (0.4)	1 (14.3)	1 (14.3)	5 (71.4)	-	-	-	-

*Age groups <30 and 30–39 years were combined to <40 due to small group size.
**Diabetes type was not included in the regression models as there was no convergence.
^One person with missing ethnicity data was removed from the regression analysis.
‡ p-value derived from log-binomial regression model adjusted for age, sex, ethnicity and area-level deprivation, testing whether the relative risk differs from 1.
CI = confidence interval.

Table 4: Interrupted care from ophthalmology review in Te Toka Tumai Auckland, 2008–2019.

Characteristics		Eligible population N (col%)	Ophthalmology review status			Complete loss to follow-up vs no interrupted care/delayed care N=1,135^		Delayed care vs no interrupted care N=947^	
			Complete loss to follow-up	Delayed care	No interrupted care	Relative risk (95% CI)	p-value‡	Relative risk (95% CI)	p-value‡
			N (row%)	N (row%)	N (row%)				
Total	-	1,136 (100.0)	188 (16.5)	366 (32.2)	582 (51.2)	-	-	-	-
Sex	Female	509 (44.8)	84 (16.5)	173 (34.0)	252 (49.5)	Ref	-	Ref	-
	Male	627 (55.2)	104 (16.6)	193 (30.8)	330 (52.6)	0.91 (0.70–1.18)	0.4843	0.92 (0.78–1.08)	0.3000
Age (years)	<40*	53 (4.7)	18 (34.0)	16 (30.2)	19 (35.8)	1.94 (1.19–3.17)	0.0076	1.34 (0.90–1.99)	0.1510
	40–49	76 (6.7)	25 (32.9)	24 (31.6)	27 (35.5)	1.89 (1.21–2.95)	0.0052	1.25 (0.88–1.79)	0.2090
	50–59	199 (17.5)	33 (16.6)	61 (30.7)	105 (52.8)	Ref	-	Ref	-
	60–69	292 (25.7)	47 (16.1)	100 (34.2)	145 (49.7)	1.00 (0.67–1.51)	0.9847	1.10 (0.86–1.42)	0.4390
	70–79	297 (26.1)	36 (12.1)	90 (30.3)	171 (57.6)	0.71 (0.46–1.10)	0.1226	0.95 (0.73–1.23)	0.6780
	80+	219 (19.3)	29 (13.2)	75 (34.2)	115 (52.5)	0.72 (0.45–1.15)	0.1642	1.05 (0.80–1.38)	0.7130
Ethnicity	NZ European	296 (26.1)	60 (20.3)	86 (29.1)	150 (50.7)	Ref	-	Ref	-
	Asian	385 (33.9)	65 (16.9)	117 (30.4)	203 (52.7)	0.87 (0.63–1.20)	0.3974	1.03 (0.82–1.28)	0.8290
	Māori	108 (9.5)	20 (18.5)	42 (38.9)	46 (42.6)	0.90 (0.57–1.42)	0.6481	1.31 (0.98–1.74)	0.0650
	Pacific peoples	312 (27.5)	38 (12.2)	110 (35.3)	164 (52.6)	0.60 (0.40–0.89)	0.0121	1.13 (0.89–1.43)	0.3250
	Other	34 (3.0)	5 (14.7)	11 (32.4)	18 (52.9)	0.70 (0.30–1.62)	0.4019	1.00 (0.61–1.66)	0.9950
	Missing	1 (0.1)	0 (0.0)	0 (0.0)	1 (100.0)	-	-	-	-

Table 4 (continued): Interrupted care from ophthalmology review in Te Toka Tumai Auckland, 2008–2019.

Characteristics		Eligible population N (col%)	Ophthalmology review status			Complete loss to follow-up vs no interrupted care/delayed care N=1,135^		Delayed care vs no interrupted care N=947^	
			Complete loss to follow-up	Delayed care	No interrupted care	Relative risk (95% CI)	p-value‡	Relative risk (95% CI)	p-value‡
			N (row%)	N (row%)	N (row%)				
Area-level deprivation (quintiles)	1 (least deprived)	126 (11.1)	24 (19.0)	38 (30.2)	64 (50.8)	Ref	-	Ref	-
	2	215 (18.9)	38 (17.7)	79 (36.7)	98 (45.6)	1.11 (0.71–1.74)	0.6538	1.21 (0.89–1.63)	0.2200
	3	282 (24.8)	47 (16.7)	82 (29.1)	153 (54.3)	1.03 (0.66–1.60)	0.9031	0.93 (0.69–1.27)	0.6630
	4	172 (15.1)	18 (10.5)	56 (32.6)	98 (57.0)	0.63 (0.36–1.11)	0.1106	0.91 (0.65–1.27)	0.5860
	5 (most deprived)	341 (30.0)	61 (17.9)	111 (32.6)	169 (49.6)	1.11 (0.71–1.72)	0.6555	0.98 (0.73–1.33)	0.9210
Diabetes type**	Type 1	110 (9.7)	24 (21.8)	43 (39.1)	43 (39.1)	-	-	-	-
	Type 2	1,015 (89.3)	162 (16.0)	320 (31.5)	533 (52.5)	-	-	-	-
	Other	6 (0.5)	2 (33.3)	2 (33.3)	2 (33.3)	-	-	-	-
	Missing	5 (0.4)	0 (0.0)	1 (20.0)	4 (80.0)	-	-	-	-

*Age groups <30 and 30–39 years were combined to <40 due to small group size.
**Diabetes type was not included in the regression models as there was no convergence.
^One person with missing ethnicity data was removed in the regression analysis.
‡ p-value derived from log-binomial regression model adjusted for age, sex, ethnicity and area-level deprivation, testing whether the relative risk differs from 1.
CI = confidence interval.

Ideally such analyses would be possible in New Zealand so that we can evaluate efforts to improve access to care and avoid vision loss from diabetes.

Reasons for the interrupted care we observed are likely to be multifactorial, with a combination of service- and patient-related factors involved. Service-related factors, such as delays in appointment scheduling, inflexible appointment times, poor communication with patients, geographic distance from eye services and transport links, reduce a person's ability to access timely services in many settings including New Zealand.[26–28] During the study period, diabetes eye services in Te Toka Tumai Auckland was predominantly run from a single hospital setting with a relatively expensive car park that is frequently full. This centralised service and car park were key barriers expressed by people disconnected from care at Auckland diabetes eye services that was not shared by people enrolled at Counties Manukau, which has a more decentralised service.[28] The mobile screening service in Te Tai Tokerau provides another example of a service delivery strategy that can assist with improving access to eye care services for people with diabetes.[10,29]

Patient-related barriers include discordance between presence of diabetic retinopathy and patient awareness of having diabetic retinopathy,[28,30] self-perceived need for eye services, and time constraints (e.g., work and family commitments).[28,31] A key finding of our analysis is the higher complete loss to follow-up from retinal screening among younger adults (30–39 years and 40–49 years) compared with people aged 50–59 years. This may reflect higher mobility among this age group compared to older adults, and they may be accessing services in other regions.[32] However, given this younger group have decades of care ahead of them to maximise their health, they are an important group to focus on when planning how to improve access to diabetes eye care.[33] Our finding that there were fewer differences between population groups in loss to follow-up at the referral and ophthalmology review stages may be explained by an increased self-perception of need for services if they are experiencing vision loss or other impacts on their day-to-day functioning, whereas many people at retinal screening are likely asymptomatic.[34]

Among underserved groups, barriers in accessing eye care are even greater, and consequently it is unsurprising that their loss to follow-up rates are higher.[35] The *Pae Ora (Healthy Futures) Act*, launched in 2022, and the *New Zealand Health Strategy* emphasise the role of the health system in improving equity and access through people-centred approaches.[36] To achieve equity in diabetes eye services, these approaches need to address systemic barriers that disproportionately affect underserved groups. Indeed, we have extensive evidence on barriers experienced by underserved groups with diabetes when accessing eye care[28,35,38] or other health services.[39] Future efforts must move towards developing and evaluating solutions that improve access to eye care for people with diabetes.[40] Fortunately, there is evidence on successful strategies used elsewhere on which we can draw, including moving screening to primary care or community settings via teleretinal screening[41,42] or mobile services,[43] and AI-assisted screening.[44] The impact of any new interventions on equity must be monitored to avoid unintended widening of health disparities.[37]

Our results should be interpreted in the context of several limitations. First, the available data did not include the follow-up period decided at each individual consultation, so we used generic follow-up intervals for each stage of the pathway. The recommended follow-up period may have been shorter for some people who were assessed to be at higher risk of developing diabetic retinopathy,[24] so we may have under-estimated delayed care at all stages of the care pathway. Second, due to how ophthalmology services are coded, there was no ophthalmology consultation code specific to diabetic retinopathy. However, as this cohort was created from people who were referred from retinal screening, any ophthalmology consultations provided to people in the cohort for reasons unrelated to diabetic retinopathy will likely be small enough to not inflate the loss to follow-up rates at the referral and ophthalmology review stages reported here. Third, because we used retinopathy grading as the criteria to assign need for referral, we have not assessed time to ophthalmology appointment for people referred for other reasons, such as severe maculopathy in the absence of referrable retinopathy, poor image quality or cataract. If some of these people were experiencing reduced vision, they may be prioritised in the referral process, or their care-seeking may be more proactive compared to the generally asymptomatic people included in our analysis, meaning we may have over-estimated interrupted care by omitting these groups from our analysis.

In conclusion, our study found high levels of loss to follow-up and delayed care at every stage of the diabetes eye care pathway in Auckland, with pronounced differential access observed between population groups for retinal screening. Interrupted care is likely to contribute to vision loss, particularly as diabetic retinopathy is asymptomatic until it reaches an advanced stage.

COMPETING INTERESTS
Nil.

ACKNOWLEDGEMENTS
*Dr David Squirrel died after submission of this manuscript. We acknowledge his contribution to this analysis and his commitment to strengthening diabetes eye care in Aotearoa New Zealand.
We acknowledge the Health Research Council of New Zealand for the funding support. We also acknowledge the National Collections Department of the Ministry of Health – Manatū Hauora, the Ministry of Health – Manatū Hauora and Health New Zealand – Te Whatu Ora Te Toka Tumai Auckland Greenlane Clinical Centre who provided data and guidance.
Data availability statement: Raw data obtained from Te Toka Tumai Auckland and the National Collections Department of the Ministry of Health – Manatū Hauora were provided under the auspices of ethical and locality approvals, which prohibit the onward sharing of these data. Therefore, data used in this analysis cannot be shared publicly. However, researchers could follow our procedure to request the data.

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URL
https://nzmj.org.nz/journal/vol-139-no-1637/interrupted-diabetes-eye-care-in-te-toka-tumai-auckland-2008-2019-analysis-of-routinely-collected-health-facility-data

CITATION
Silwal PR, Pirouzi M, Lee A, et al. Interrupted diabetes eye care in Te Toka Tumai Auckland 2008–2019: analysis of routinely collected health-facility data. N Z Med J. 2026 Jun 26;139(1637):14-35. doi: 10.26635/6965.7237.

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Appendices

Appendix 1: Diabetic retinopathy grading classification and referral guidance, Ministry of Health – Manatū Hauroa, New Zealand.

Retinopathy grade*	Guidance
No retinopathy (R0)	Re-screen at 2 years for type 1 diabetes Re-screen at 2–3 years for type 2 diabetes *The interval depends on the presence of clinical modifiers (risk factors). The re-screening interval can be extended to 3 years for some low-risk patients.*
Minimal retinopathy (R1)	Re-screen at 2 years *The interval depends on the presence of clinical modifiers (risk factors).*
Mild retinopathy (R2)	Re-screen after 12 months *For type 2 diabetes, the interval may be extended to 18 months if the HbA_{1c} is <64mmol/mol.*
Moderate retinopathy (R3)#	Re-screen at 6 months *If HbA_{1c} >75mmol/mol, consider review by ophthalmologist within 4 months.*
Severe retinopathy (R4)	Review by ophthalmologist within 6 weeks
Proliferative retinopathy (R5)	Urgent referral to ophthalmologist; consider review within 2 weeks

Source: Ministry of Health – Manatū Hauora. Diabetic Retinal Screening, Grading, Monitoring and Referral Guidance [Internet]. Wellington, New Zealand: 2026 May [cited 2026 Jun 15]. Available from: https://www.healthnz.govt.nz/health-professionals/guidance-standards/topic/conditions/diabetes/diabetes-complications

*Grading is based on the grade in the worst eye.

#Moderate retinopathy (R3) is the threshold for patient referral to ophthalmic care.

Appendix 2: Detailed descriptions of the outcome variables for interrupted diabetes eye care.

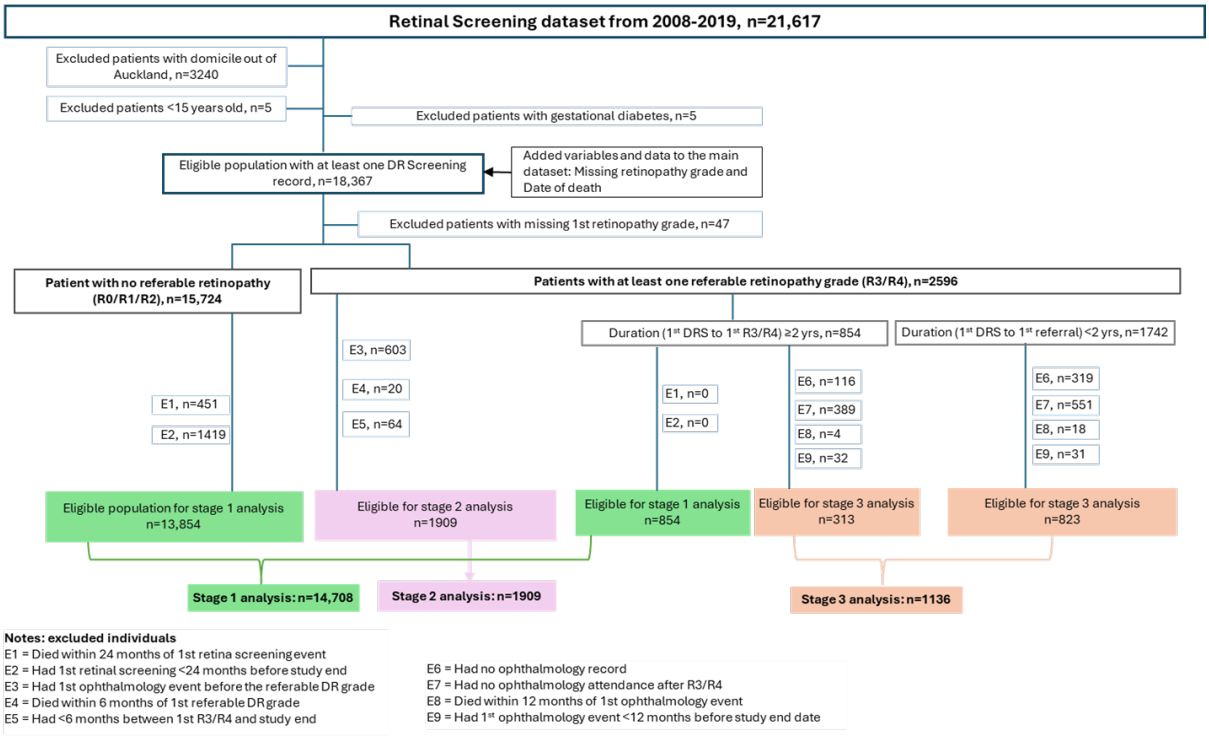
Interrupted care from retinal screening (stage 1)		
Descriptions	**Population sub-group 1**	**Population sub-group 2**
Denominator (eligible population)	Everyone who attended at least one retinal screening event prior to 1 January 2018, never had referable retinopathy and lived at least 24 months from their first attended retinal screening event	Everyone who attended at least one retinal screening event prior to 1 January 2018, had a referable retinopathy diagnosed after at least 24 months of the first retinal screening event and lived at least 24 months from their first attended retinal screening event
Follow-up period	Start = the date of their first screening event attended; end = whichever occurred first of their date of referral to ophthalmology (i.e., when referable retinopathy identified [R3/R4]), their date of death or the end of the study period (31 December 2019)	
Numerator	The number of expected retinal screening events during the follow-up period for each individual was calculated based on at least one anticipated screening event in each 24-month period after the first screening event*	
	Complete loss to follow-up = proportion of the eligible population who attended none of their expected retinal screening events during the follow-up period	
	Delayed care = proportion of the eligible population who missed at least one of their expected retinal screening events during the follow-up period	
Interrupted care when referred from retinal screening to ophthalmology services (stage 2)		
Component	**Description**	
Denominator (eligible population)	Everyone with at least one event prior to 1 July 2019 at which they were diagnosed with referable retinopathy and past which they lived at least 6 months (to allow 6 months for them to reach ophthalmology before the study end date of 31 December 2019)	
Follow-up period	Start = the date they were diagnosed with referable retinopathy at retinal screening; end = whichever occurred first of their date of death, attended ophthalmology event or the end of the study period (31 December 2019)	
Numerator	Complete loss to follow-up = proportion of the eligible population who did not access an ophthalmology appointment at any point after being diagnosed with referable retinopathy	
	Delayed care = proportion of the eligible population who accessed at least one of their ophthalmology appointments, but did so more than 6 months after being diagnosed with referable retinopathy	

Appendix 2 (continued): Detailed descriptions of the outcome variables for interrupted diabetes eye care.

Interrupted care from ophthalmology review (stage 3)	
Component	**Description**
Denominator (eligible population)	Everyone with at least one event prior to 1 January 2019 at which they were diagnosed with a referable retinopathy and past which they attended at least one ophthalmology event prior to 1 January 2019 and lived at least 12 months from their first attended ophthalmology event
Follow-up period	Start = the date of their first ophthalmology event attended; end = whichever occurred first of their date of death or the end of the study period (31 December 2019)
Numerator	The number of expected ophthalmology events during the follow-up period for each individual was calculated based on at least one anticipated ophthalmology event in each 12-month period after the first ophthalmology event
	Complete loss to follow-up = proportion of the eligible population who attended none of their expected ophthalmology events during follow-up
	Delayed care = proportion of the eligible population who missed at least one of their expected ophthalmology events during follow-up

*__Source:__ Ministry of Health – Manatū Hauora. Diabetic Retinal Screening, Grading, Monitoring and Referral Guidance [Internet]. Wellington, New Zealand: 2026 May [cited 2026 Jun 15]. Available from: https://www.healthnz.govt.nz/health-professionals/guidance-standards/topic/conditions/diabetes/diabetes-complications

Appendix 3: Summary of the study population eligible for interrupted analysis.

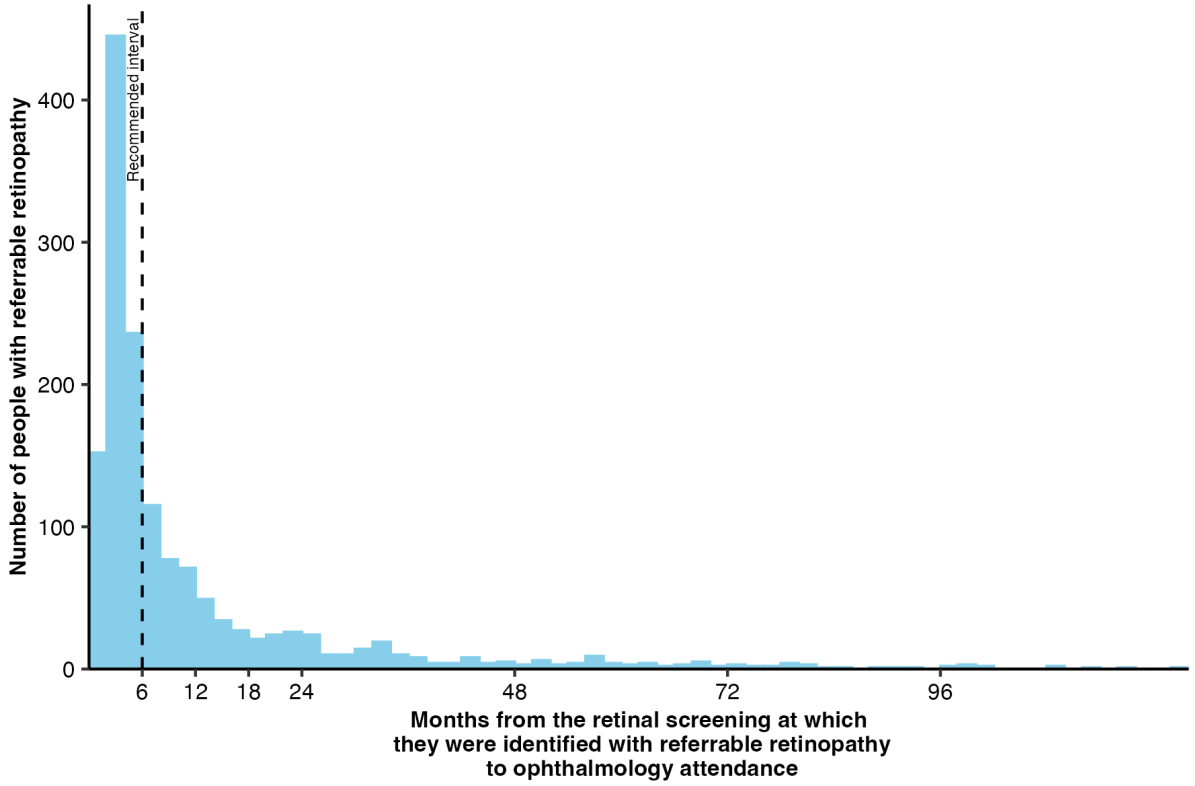


Appendix 4: Sensitivity analysis of interrupted care from diabetes eye care services pathways in Te Toka Tumai Auckland, 2008–2019, with an additional 2 months for follow-up.

Stages in the care pathways	Complete loss to follow-up	Delayed care	No interrupted care	Total
	n (row%)	n (row%)	n (row%)	
Retinal screening (stage 1)	2,970 (20.2%)	3,882 (26.4%)	7,856 (53.4%)	14,708 (100.0%)
Referred from retinal screening to ophthalmology services (stage 2)	433 (22.7%)	578 (30.3%)	898 (47.0%)	1,909 (100.0%)
Ophthalmology review (stage 3)	188 (16.6%)	287 (25.3%)	661 (58.2%)	1,136 (100.0%)

Complete loss to follow-up = when an individual never attended the expected next event; delayed care = when an individual attended the expected next event, but not within the expected time frame (26 months for retinal screening, 8 months for referral and 14 months for ophthalmology review).

Appendix 5: Months between being identified with referrable diabetic retinopathy and attending an ophthalmology appointment.



Appendix 6: Distribution of attendance at retinal screening and ophthalmology review by the number of expected events.

At retinal screening (stage 1)		
Number of expected retinal screening events	Number of people with the expected number of events	Attended all expected retinal screening events n (%)
2	2,627	1,921 (73.1)
3	2,667	1,673 (62.7)
4	3,080	1,669 (54.2)
5	2,913	993 (34.1)
6	3,421	1,011 (29.6)
At ophthalmology review (stage 3)		
Number of expected ophthalmology review events	Number of people with the expected number of events	Attended all ophthalmology review events n (%)
2	121	85 (70.2)
3	128	65 (50.8)
4	113	48 (42.5)
5	99	46 (46.5)
6	98	56 (57.1)
7	105	52 (49.5)
8	128	65 (50.8)
9	127	60 (47.2)
10	129	58 (45.0)
11	88	47 (53.4)