

# BMJ Open Awareness of diabetic retinopathy and its association with attendance for systematic screening at the public primary care setting: a cross-sectional study in Hong Kong

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## ABSTRACT

**Objective** To assess the association between awareness of diabetic retinopathy (DR) and actual attendance for DR screening.

**Design** Cross-sectional study.

**Setting** Two public general outpatient clinics.

**Participants** The subjects were people with diabetes mellitus (DM) who participated in a randomised controlled trial, set up in 2008, to test the impact of a copayment on attendance for DR screening.

**Primary and secondary outcome measures** The subjects' awareness of DR was evaluated using a structured questionnaire conducted via a telephone interview. The attendance for screening was from the actual attendance data. Association between awareness and attendance for screening was determined using multivariate logistic regression model and was reported as ORs.

**Results** A total of 2593 participants completed the questionnaire. A total of 42.9% (1113/2593) said they would worry if they had any vision loss and 79.6% (2063/2593) knew that DM could cause blindness. Only 17.5% (453/2593) knew that treatment was available for DR and 11.5% (297/2593) knew that early DR could be asymptomatic. The importance of having a regular eye examination was acknowledged by 75.7% (1964/2593), but 34% (881/2593) did not know how frequently their eyes should be examined. Worry about vision loss (OR=1.72, P<0.001), awareness of the importance of regular eye examination (OR=1.83, P=0.002) and awareness of the frequency of eye examinations ('every year' (OR=2.64, P<0.001) or 'every 6 months' (OR=3.27, P<0.001)) were the most significant factors associated with attendance.

**Conclusions** Deficits in knowledge of DR and screening were found among subjects with DM, and three awareness factors were associated with attendance for screening. These factors could be targeted for future interventions.

## INTRODUCTION

According to the WHO, screening is 'the presumptive identification of unrecognized

## Strengths and limitations of this study

- The actual attendance data were collected prospectively, which overcame the errors in recall and reverse causality.
- The sample size was over 2000 subjects, which gave sufficient statistical power to test a number of variables indicating awareness.
- One limitation is the generalisability of the results to subjects with diabetes who are looked after in secondary care.

disease in an apparently healthy, asymptomatic population by means of tests, examinations or other procedures which can be applied rapidly'.<sup>1</sup> An individual's awareness is postulated as one of the predisposing factors that influence the individual's behaviour, for example, attendance for screening.<sup>2,3</sup>

Diabetic retinopathy (DR), a common complication of diabetes mellitus (DM), has become the leading cause of new cases of blindness among people of working age in developed countries.<sup>4</sup> However, DR can be asymptomatic until there is significant vision loss. Therefore, early detection plays an important role in preventing blindness resulting from DR. Iceland and the UK are two countries that adopted systematic DR screening early.<sup>5,6</sup> Iceland has successfully reduced the prevalence of blindness in the diabetic population from 2.4% to 0.5% between 1980 and 1994.<sup>5</sup> The incidence of sight impairment and severe sight impairment in the diabetic population was found to be almost halved in Wales over an 8-year period up to 2015.<sup>7</sup> Screening for DR has also been shown to be a cost-effective intervention to prevent vision loss.<sup>8-10</sup>

Regular screening for DR is recommended in many clinical guidelines,<sup>11–13</sup> but in practice only 58%–81% of all patients with DM were regularly screened, as reported from studies in Ireland, USA, Turkey and the Netherlands.<sup>2 14–18</sup> Even in the systematic DR screening programmes in the UK, attendance rates have varied between 55% and 95%.<sup>19</sup> Non-attendance for screening, apart from wasting resources, was also associated with increased risk of developing sight-threatening diabetic retinopathy (STDR).<sup>20–22</sup> Why some people do not attend is an important issue to understand and address in order to better manage the risk of DM complications and efficient resource allocation.

Awareness of DR and its implications for vision is an important prerequisite for attendance for screening, and it has been examined in subjects with diabetes, with highly variable findings across different ethnic populations.<sup>2 17 23–27</sup> However, few studies have examined the association of awareness with attendance for screening. In general, lack of awareness was found to be an obstacle to attendance for screening. The types of awareness measured were knowledge of detrimental effects of DR on visual acuity, knowledge of DM on DR, whether physicians or healthcare providers had recommended regular eye examinations, awareness of the need for regular and frequency of screening, and concern for vision loss.<sup>2 17 26 28 29</sup> Among those studies that examined the association between screening and awareness, attendance for screening was usually collected retrospectively from self-reported data or review of medical chart. This cannot eliminate reverse causality (ie, those who were screened have more knowledge because they went to screening rather than the knowledge itself that made them go) and potential error in recall if it was self-reported data (eg, mistaking tests for spectacle prescription for retinal examination for DR).

To date, there are few studies on awareness of DR and its association with attendance for screening in Chinese populations.<sup>24 29</sup> Cultural, social and geographical factors could limit generalisation of the results found elsewhere to Chinese populations. Hong Kong (HK) offers a good venue to study the response in a majority of Chinese population, where DR screening is offered through a systematic call and recall system at the public primary care level with only a small copayment.<sup>30 31</sup>

Using data collected from a randomised controlled trial (RCT) study of DR screening carried out in HK, we aimed to assess the association between awareness of DR and actual attendance for screening from a cross-sectional study.

## METHODS

In 2008, we set up an RCT to test the impact of a copayment on attendance for screening.<sup>30 31</sup> In that study, as well as collecting information on financial barriers to attendance for screening at a public general outpatient

clinic (GOPC), we asked questions on awareness of DR and screening.

## Participants

The participants were people with an existing diagnosis of DM recorded in their computerised medical records and who attended one of two neighbouring public GOPCs. The whole group of 4644 subjects were randomised into a free screening group without any copayment or a pay group with a copayment of HK\$60 (about £5). Of these subjects, 2593 agreed to participate in the study, with 1316 in the free group and 1277 in the pay group. All the participants completed a structured questionnaire by telephone. They were then invited for DR screening with or without a copayment according to their group allocation at the end of the telephone call. Finally, 2217 subjects attended screening, an attendance rate of 85.5% (2217/2593). The research adhered to the tenets of the Declaration of Helsinki, and all participants gave informed consent before taking part. Full details of the study design and subject recruitment are published elsewhere.<sup>30 31</sup>

## Data collection

The subjects' awareness of DR and its implications was evaluated using a structured questionnaire with previously validated questions from the literature as far as possible.<sup>2 15 32</sup> These questions were translated into Chinese, and the questionnaire was piloted in face-to-face interviews on 15 randomly selected subjects with DM in the community or in a hospital-based clinic to test understanding and acceptability. No problems were found for this part.

## Data analysis

A descriptive analysis was used to summarise the characteristics of participating subjects. Variables indicating awareness of DR are listed below and include nine questions, most of which have three response categories, that is, yes, no or don't know, except for a few questions as specified.

1. AD1: 'At the present time, how would you rate your eyesight using both eyes (with glasses or contact lenses, if you wear them)?' with a six-category response scale from excellent to completely blind.
2. AD2: 'Do you worry if you have any vision loss?'
3. AD3: 'Do you know if diabetes could affect blindness (retinopathy)?'
4. AD4: 'Do you think it is important to have regular eye examinations?'
5. AD5: 'Have you ever been recommended by a doctor to have regular eye examinations?'
6. AD6: 'How often do you think your eyes should be examined if you are diabetic?' with a five-scale choice from never to every 6 months and don't know.
7. AD7: 'Do you believe early diabetic retinopathy is symptomatic?'

8. AD8: 'Do you aware that there is treatment available for diabetic retinopathy?'
9. AD9: 'Have your eyes ever been screened by a general practitioner for diabetic retinopathy?'

Most of these variables did not need recoding, except for self-rated eyesight (question AD1) for which the original six-category scale was recoded to three categories of good (including excellent and good), fair and poor (including poor, very poor and completely blind).

These variables were compared between those who did and did not attend screening by  $X^2$  test, and those variables that differed significantly between the groups were included into a multivariate logistic regression model with attendance for screening as the dependent variable. The model was adjusted for age, sex, marital status, socio-economic status (ie, education level, occupation, whether receiving comprehensive social security assistance, family income, housing type) and the fee group allocation. Missing age (98% complete) was replaced by the median value of the self-reported age group and used in the logistic regression model. We report ORs and their 95% CI with a P value of 0.05 being considered significant. All analyses were performed using STATA V.13.

## RESULTS

The 2593 participants had a mean age of 64 years, a mean duration of diabetes of 7.6 years, mean haemoglobin A1c of 7.5% and mean blood pressure of 139/78mm Hg (table 1).

Most (2237/2593, 86.3%) participants rated themselves to have good eyesight, 42.9% (1113/2593) would worry if they had any vision loss and 79.6% (2063/2593) knew diabetes could affect blindness (retinopathy), but only 17.5% (453/2593) knew treatment was available for DR and 11.5% (297/2593) knew early DR could be asymptomatic (table 2). The importance of DR screening was acknowledged by 75.7% (1964/2593), and 58.9% (1528/2593) thought that their eyes should be examined every 6–12 months, but 34% (881/2593) did not know how frequently their eyes should be examined. Only 15.8% (409/2593) reported having been recommended by a doctor to have a regular eye examination and 13.0% (337/2593) to have been screened by a general practitioner (GP) for DR.

Subjects who attended DR screening reported higher proportions of worrying about vision loss (45.7% vs 26.3%,  $P<0.001$ ), knowing that diabetes could lead to blindness (80.6% vs 73.4%,  $P=0.004$ ), being aware of the importance of regular eye examination (79.0% vs 56.4%,  $P<0.001$ ) and the need for yearly or more frequent screening (every year: 39.6% vs 28.7%; every 6 months: 22.5% vs 11.7%,  $P<0.001$ ), being recommended by a doctor to have an eye examination (16.2% vs 13.3%,  $P=0.019$ ), and previously screened by a GP for DR (13.7% vs 8.8%,  $P=0.011$ ), than those who did not attend (table 2).

In the adjusted logistic regression model, worry about vision loss (OR=1.72,  $P<0.001$ ), awareness of

**Table 1** Characteristics of participants

Variables	n=2593 (%)	
Mean age (SD)	64 (11)	n=2540
Female	1422 (54.8)	
Marital status		
Married	1917 (73.9)	
Single	676 (26.1)	
Educational level		
No schooling	773 (29.8)	
Primary	970 (37.4)	
Secondary	733 (28.3)	
Sixth form and up	117 (4.5)	
Current occupation		
Employed	847 (32.7)	
Retired	908 (35.0)	
Home maker	832 (32.1)	
Refuse to answer	6 (0.2)	
Receiving welfare payments (yes)	220 (8.5)	
Family income/month (HK\$)		
0–9999	815 (31.4)	
10000–19 999	580 (22.4)	
20000 or above	310 (12.0)	
Refuse to answer/don't know	888 (34.3)	
Duration of diabetes in years (SD)	7.6 (7.0)	n=2513
Mean systolic blood pressure (SD)	138.5 (12.8)	n=2542
Mean diastolic blood pressure (SD)	78.0 (8.5)	n=2542
Haemoglobin A1c, % (SD)	7.5 (1.3)	n=1852

the importance of regular eye examination (OR=1.83,  $P=0.002$ ) and thinking that eye examinations should be every year (OR=2.64,  $P<0.001$ ) or every 6 months (OR=3.27,  $P<0.001$ ) compared with less often were significantly associated with attendance for screening (table 3).

## DISCUSSION

The data for this study were collected at the time when systematic DR screening was set up as a pilot in 2008 and conducted annually. We found that our subjects had good awareness of DM as a potential cause of blindness (79.6%) and of the importance of regular eye examination (75.7%). However, there were specific deficits in knowledge, including the fact that early DR can be asymptomatic (11.5% knew) and that treatment is available for DR (17.5% knew). There were 58.9% subjects who thought screening should be performed at least once a year (ie, every year or every 6 months), but there was still 34% who did not know how often they should be screened. These knowledge deficits have also been identified in other populations, for example in Ireland, Turkey and USA.<sup>2 16 25</sup> Awareness of DR in our study

**Table 2** Awareness of diabetic retinopathy by attendance and non-attendance for screening

	Total, n=2593 (%)	Attendance for screening, n=2217 (%)	No attendance for screening, n=376 (%)	P value*
At present time, how would you rate your eyesight using both eyes (with glasses or contact lenses, if you wear them)?				
Good	2237 (86.3)	1903 (85.8)	334 (88.8)	
Fair	325 (12.5)	288 (13.0)	37 (9.8)	
Poor	31 (1.2)	26 (1.2)	5 (1.3)	0.229
Do you worry if you have any vision loss?				
No	1348 (52.0)	1094 (49.4)	254 (67.6)	
Yes	1113 (42.9)	1014 (45.7)	99 (26.3)	
Don't know	132 (5.1)	109 (4.9)	23 (6.1)	<0.001
Do you know if diabetes would affect blindness (retinopathy)?				
No	25 (1.0)	22 (1.0)	3 (0.8)	
Yes	2063 (79.6)	1787 (80.6)	276 (73.4)	
Don't know	505 (19.5)	408 (18.4)	97 (25.8)	0.004
Do you believe early diabetic retinopathy is symptomatic?				
No	297 (11.5)	245 (11.1)	52 (13.8)	
Yes	504 (19.4)	443 (20.0)	61 (16.2)	
Don't know	1792 (69.1)	1529 (69.0)	263 (70.0)	0.103
Do you aware that there is treatment available for diabetic retinopathy?				
No	2140 (82.5)	1824 (82.3)	316 (84.0)	
Yes	453 (17.5)	393 (17.7)	60 (16.0)	0.403
Do you think it is important to have regular eye examinations?				
No	259 (10.0)	176 (7.9)	83 (22.1)	
Yes	1964 (75.7)	1752 (79.0)	212 (56.4)	
Don't know	370 (14.3)	289 (13.0)	81 (21.5)	<0.001
How often do you think your eyes should be examined if you are diabetic?				
Never	33 (1.3)	22 (1.0)	11 (2.9)	
Less often	151 (5.8)	94 (4.2)	57 (15.2)	
Every year	986 (38.0)	878 (39.6)	108 (28.7)	
Every 6 months	542 (20.9)	498 (22.5)	44 (11.7)	
Don't know	881 (34.0)	725 (32.7)	156 (41.5)	<0.001
Have you ever been recommended by a doctor to have regular eye examination?				
No	2159 (83.3)	1841 (83.0)	318 (84.6)	
Yes	409 (15.8)	359 (16.2)	50 (13.3)	
Don't know	25 (1.0)	17 (0.8)	8 (2.1)	0.019
Have your eyes ever been screened by a general practitioner for diabetic retinopathy?				
No	2242 (86.5)	1903 (85.8)	339 (90.2)	
Yes	337 (13.0)	304 (13.7)	33 (8.8)	
Don't know	14 (0.5)	10 (0.5)	4 (1.1)	0.011

\*P value by  $\chi^2$  test for the comparison between attendance and non-attendance for screening.

population was generally higher than those found in surveys conducted in mainland China.<sup>24-29</sup> One study by Liu and Chen<sup>24</sup> showed that only 36.6% (174/475) of subjects with DM were aware of DR as a diabetic complication that could result in blindness. Another study by Wang *et al*<sup>29</sup> showed that 76.7% (632/824) of subjects were aware of DM affecting the eyes, but only 49.4%

(407/824) thought regular eye examinations were necessary.

We identified that worry about vision loss, awareness of the importance of regular eye examinations and awareness of the frequency of screening were the most important factors associated with attendance for screening. This is consistent with studies that found subjects' awareness

**Table 3** Adjusted associations between awareness of diabetic retinopathy and attendance for screening (n=2593)

Variable	OR*	95% CI	P value
Do you worry if you have any vision loss?			
No	1.00		
Yes	1.72	1.31 to 2.26	<0.001
Don't know	1.04	0.63 to 1.70	0.881
Do you know if diabetes would affect blindness (retinopathy)?			
No	1.00		
Yes	0.48	0.13 to 1.69	0.251
Don't know	0.49	0.13 to 1.75	0.271
Do you think it is important to have regular eye examinations?			
No	1.00		
Yes	1.83	1.24 to 2.70	0.002
Don't know	1.17	0.77 to 1.77	0.464
How often do you think your eyes should be examined if you are diabetic?			
Less often	1.00		
Never	0.93	0.40 to 2.15	0.858
Every year	2.64	1.65 to 4.22	<0.001
Every 6 months	3.27	1.92 to 5.56	<0.001
Don't know	2.11	1.38 to 3.25	0.001
Have you ever been recommended by a doctor to have regular eye examination?			
No	1.00		
Yes	1.03	0.73 to 1.46	0.847
Don't know	0.39	0.16 to 0.98	0.044
Have your eyes ever been screened by a general practitioner for diabetic retinopathy?			
No	1.00		
Yes	1.16	0.78 to 1.73	0.457
Don't know	0.80	0.23 to 2.74	0.718

\*The logistic regression model is adjusted for demographic variables (age, sex, marital status), socioeconomic status (education level, occupation, whether receiving comprehensive social security assistance, family income, housing type) and whether charged a copayment for screening.

of eye examinations being needed every 6 months was a significant predictor for receiving DR screening in Ireland<sup>2</sup> and that subjects' awareness of needing an eye examination every 12 months was significantly associated with having a dilated eye examination in the USA.<sup>28</sup> However, we did not find an association between a doctor's recommendation to have a regular eye examination and attendance for screening as reported in other studies.<sup>2,17,28</sup> This may be because we also examined other awareness factors together in the same model. However, the proportions who reported a previous screening by a GP or that they had been recommended to have regular

eye examinations by a doctor were both less than 20% in the attenders and even lower in the non-attenders when there was no systematic DR screening. A subject's awareness of DR could be obtained from different sources, but a doctor's or healthcare provider's recommendation might be one of the most important sources and this may need to be strengthened.

The strengths of this study are that the actual attendance data were collected prospectively, which overcame the errors in recall and reverse causality inherent in some previous studies. We had over 2000 subjects, which provided sufficient statistical power to test a number of variables indicating awareness. One limitation is the generalisability of the results to subjects with DM throughout HK. Our study took place in the Hong Kong West Cluster, only one of the seven clusters of the public hospital system. However, in general, GOPC attendees across clusters have some similarities in that they are more likely to be of low socioeconomic status, more elderly and more likely to have chronic illness. Many people with DM have already experienced complications and are being cared for at the secondary level. They may have different levels of awareness of DR. This is the subject of another study.

Subjects' awareness of potential complications and their prevention is a potentially modifiable risk factor that might be improved through education. It would be useful to incorporate the need for screening and that it should be regularly scheduled, as the two most important awareness predictors for attendance found in our study, into education and/or self-management programmes for DM. A systematic review found that increasing patient awareness of DR was an effective intervention to increase screening attendance.<sup>33</sup> Once the subjects with DM are aware of DR and the need for regular screening, barriers to attendance may be reduced. This will be important in HK, where systematic screening has been set up, and also in other places such as mainland China. China has the largest number of people with diabetes in the world, numbering 114.4 million people in 2017.<sup>34</sup> DR, one of the potential complications of diabetes, substantially contributes to the risk of blindness in the Chinese diabetic population. Early detection by screening and timely treatment for STDR are effective in preventing blindness, as the successful experience from Iceland and the UK has shown. However, one of the key steps is for people with DM to attend DR screening. Given the relative underdevelopment of primary care in China, DR screening needs to rely more on self-seeking behaviour and awareness plays a key role. Why people attend screening and what influences attendance are important questions and have implications on diabetes management. Future education interventions should include raising awareness, for example, of the importance of screening and of the frequency of screening.

In conclusion, deficits in knowledge of DR and screening were found in subjects with DM, and three awareness factors were significantly associated with

attendance for screening. Future interventions should include raising awareness.

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**Contributors** JXL analysed and interpreted the data and wrote the manuscript. SMM contributed to the design of the work, interpretation of data and revised the manuscript critically for important intellectual content. RAG contributed to the acquisition of the data and revised the manuscript critically. CLKM, MKHY and DSHW substantially contributed to the design of the work, acquisition of data and revised it critically for important content. All authors approved the final version to be published.

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**Competing interests** None declared.

**Patient consent** Obtained.

**Ethics approval** Ethics approval was obtained from the Institutional Review Board of The University of Hong Kong and HA West Cluster (Institutional Review Board Reference Number UW08-134).

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