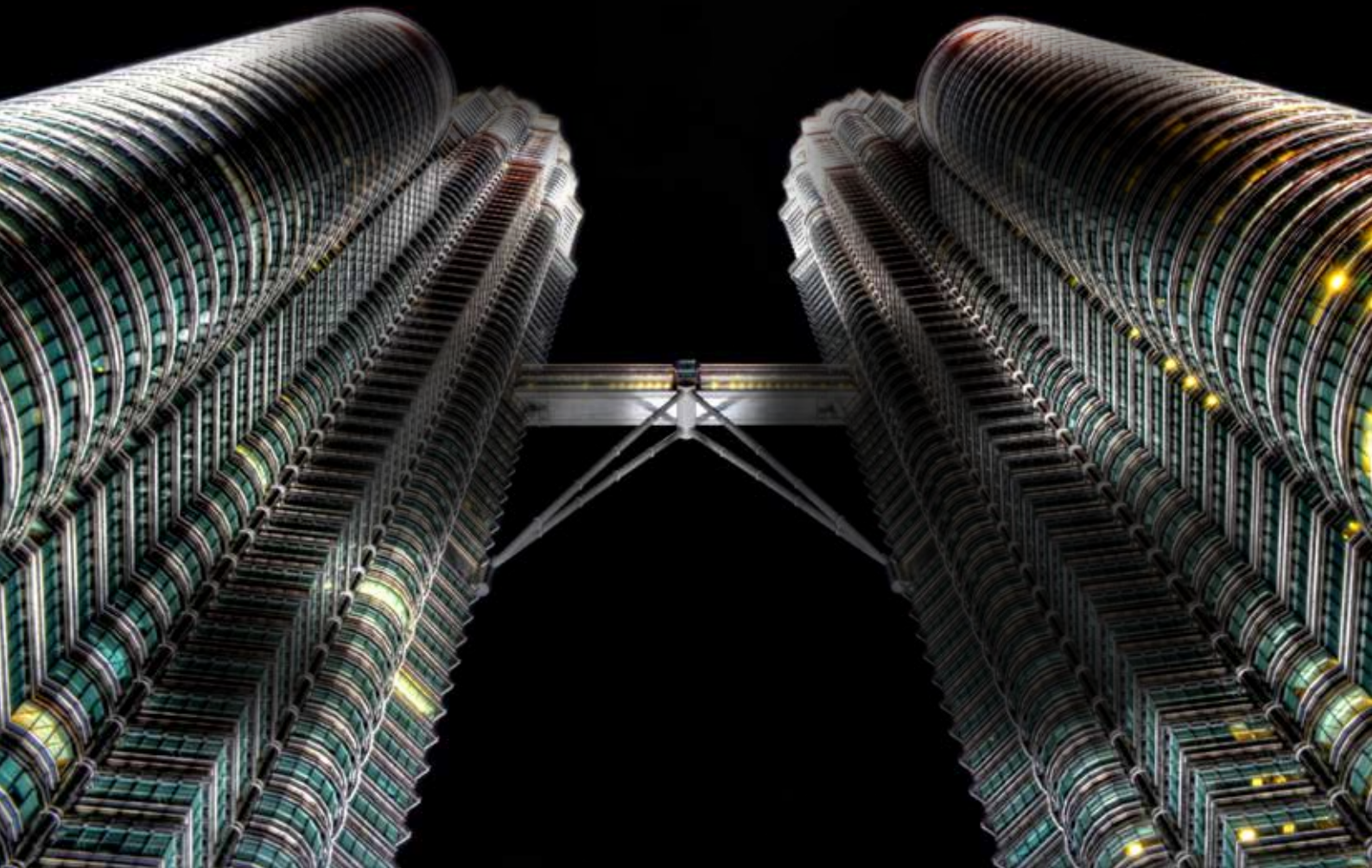


The Diabetic Retinopathy Barometer Report

# Malaysia





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For detailed information regarding methodology and limitations of the study please refer to the DR Barometer Global Results Report which can be found at [DRBarometer.com](https://DRBarometer.com)

# Introduction

## Global Study

The International Federation on Ageing, the International Diabetes Federation, and the International Agency for the Prevention of Blindness undertook a comprehensive, two-phase, multi-country study to investigate the global and specific country issues surrounding diabetic eye disease (DED) primarily, diabetic retinopathy (DR) and diabetic macular edema (DME).

This report describes the specific findings from information gathered from adults with diabetes and health care professionals in Malaysia.

All people with type 1 and type 2 diabetes are at risk of developing DR, which can lead to loss of vision and eventually to blindness. DME is a type of DR that is particularly associated with vision loss. DR is preventable by prompt diagnosis and appropriate management of diabetes.

Vision loss is preventable if DR is identified in its early stages by screening, as effective treatments are now available to prevent progression. Despite the serious risks of DR, little has been published regarding the global awareness of the risks and prevention and effective management of diabetes associated vision impairment.

This research was made possible with support from Bayer AG. Bayer has funded and facilitated this research, acted as an advisor and will assist in the dissemination of the research findings.

## Goal

The DR Barometer Study sought, in broad terms, to assess the awareness of, and access and barriers to diabetes management, including screening for DED and timely treatment.

This new information from forty-one countries is vital to understanding the barriers to improved outcomes and the actions required to overcome such barriers.

Initiatives that address the gaps in the care pathway are essential to preventing unnecessary blindness and visual impairment to enable people with diabetes to maintain their health and ensure that the contribution that they can make to family and community are not compromised.

## Background

The DR Barometer Study used a mixed methods approach. Phase I was a qualitative study comprising 120 semi-structured interviews with a small sample of people with diabetes ( $n = 9$  per country) and health care professionals ( $n = 6$  per country) in each of the eight countries: Germany, Saudi Arabia, Japan, Romania, Mexico, Argentina, Uganda, and Bangladesh. The countries were purposively selected for variation across income level and region, as delineated by the World Health Organization (WHO) and into World Bank Income Groups (WBIGs).

Phase II was a multi-country quantitative study conducted in 41 countries to investigate the current level of awareness of the risk of DR and of the need for prevention, screening and management to prevent vision loss. The study also sought to better understand the nature of health services and supports available, and the social and economic burden of the disease through a systematic literature review.

In the quantitative component of the study, both adults with diabetes (patients) and health care professionals (providers) were surveyed. The patient survey consisted of 46 questions divided into four sections covering awareness and knowledge, current care for diabetes and eye complications, screening and treatment of DR and DME, and quality of life.

The provider survey comprised 43 questions covering provider and practice characteristics, and specific information from ophthalmologists. Globally, the patient survey had a total of 4,340 respondents and the provider survey had 2,329 respondents.

Respondents from each country were grouped into regions as defined by the WHO and into the WBIGs.

## Study Populations

The people with diabetes participating in the patient survey were self-selected, predominantly from patient organisations. Therefore, this group comprises people who are more likely to be engaged and motivated in the management of their diabetes. Likewise, the provider respondents were self-selected and the same caution should be applied when interpreting the results.

Even though the sample is not representative of the broader population of people with diabetes and health care professionals, the findings illustrate important trends, and highlight areas of concern.

The results from this survey provide new evidence reflecting concerns from the voices of thousands of patients and health care professionals around the world. This study provides a rich resource for generating unique insights into the real-life experiences of people living with diabetes, and as such is a powerful tool to help improve the lives of current and future generations of people with diabetes.

For the purpose of understanding the impact of the progression of DED, responses to the patient survey, beyond “all respondents”, are reported by three subgroups:

- Without DED: people with diabetes without any reported form of DED
- With DED: people with diabetes with reported DED but not DME
- With DME: people with diabetes with reported DED and DME

As reported by 4,340 adults with diabetes who responded to the survey, 20% reported to have been diagnosed with DED and a further 7.6% with DME.

Of the health care professionals who responded to the survey (n = 2,329), 37% were ophthalmologists, 17% were diabetes specialist providers and 16% were primary care providers. The remaining respondents were optometrists, nurses, health educators or other professionals.



# Introduction

## Malaysia Study

### Demographic Characteristics<sup>1,2</sup>

Malaysia is estimated to be the sixth most populous country in East Asia with an estimated population of 30.7 million. In 2015 24% of Malaysia's population was under the age of 15 years (~7.5 million) while ~9% was over the age of 60 years (~1.7 million).

By 2050, the population distribution in Malaysia is expected to drastically change with a 34% population increase with the country actually ageing. Population over the age of 60 years is expected to increase by 447%, and those aged 14 years and under will decrease by 9%. In just 34 years, the population aged over 60 years will reach an all-time high of approximately 9.7 million, about 24% of the total population.

The ageing process will be particularly reflected by an increase in the number of those aged 80 years and over. In 2015, the number of people aged 80 years and over was ~ 242,648, which was a share of 0.8% of the country's population. That number will almost sextuple and reach an all-time high in 2050 to more than 1.6 million, about 4% of the total population.

### Diabetes Profile<sup>3</sup>

There are 415 million people living with diabetes and more than 153.2 million people are in the Western Pacific Region. By 2040, this number is expected to rise to 214.8 million.

Malaysia has the eighth highest number of people living with diabetes in the Western Pacific Region at ~3.3 million (2,969.0-3,801.9 $\pm$ ), which accounts to ~2% of people living with diabetes in this region. The diabetes national prevalence (20 – 79 years) is 16.6% (14.9-19.1 $\pm$ ), which is well above the global average of 8.8%.

Deaths attributed to diabetes in Malaysia in 2015 were 34,576, which accounts for ~3% of the diabetes related deaths experienced in this region. The estimated number of undiagnosed cases was 1.7 million (1,538.5-1,970.2 $\pm$ ).

### Study Populations: Malaysia

As reported by 110 respondents with diabetes in Malaysia, 28% were diagnosed with DED and a further 8.2% with DME.

Fifty health care professionals completed the survey in Malaysia. Of these, five were diabetes specialist providers (10%), 15 were ophthalmologists (30%), and eight were primary care providers (16%). The remaining respondents were either optometrists, nurses, health educators or other professionals.

# The DR Barometer Study: Malaysia Overview

The DR Barometer study was conducted in 41 countries. In Malaysia, 110 adults with diabetes and 50 health care professionals provided new information about the experiences of living with, managing and treating diabetes, DR and DME.

# 39%

of patients said that **long wait times for an appointment** were a barrier to eye exams



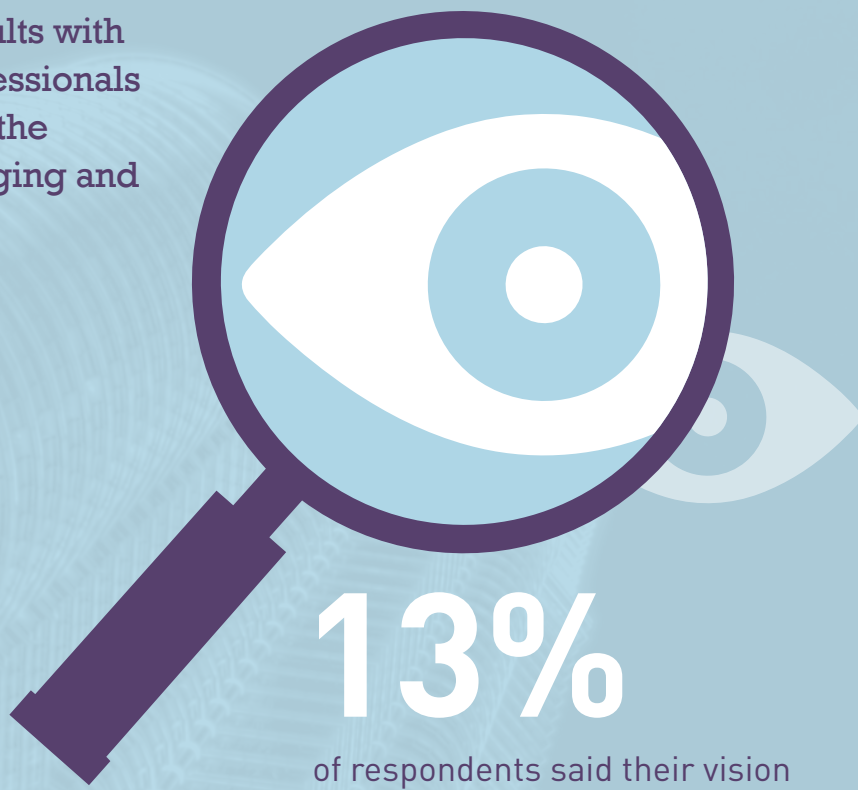
# 35%

of all providers **did not have written protocols/guidelines** for detection and management of diabetes-related vision loss available

**DR:** Diabetic Retinopathy

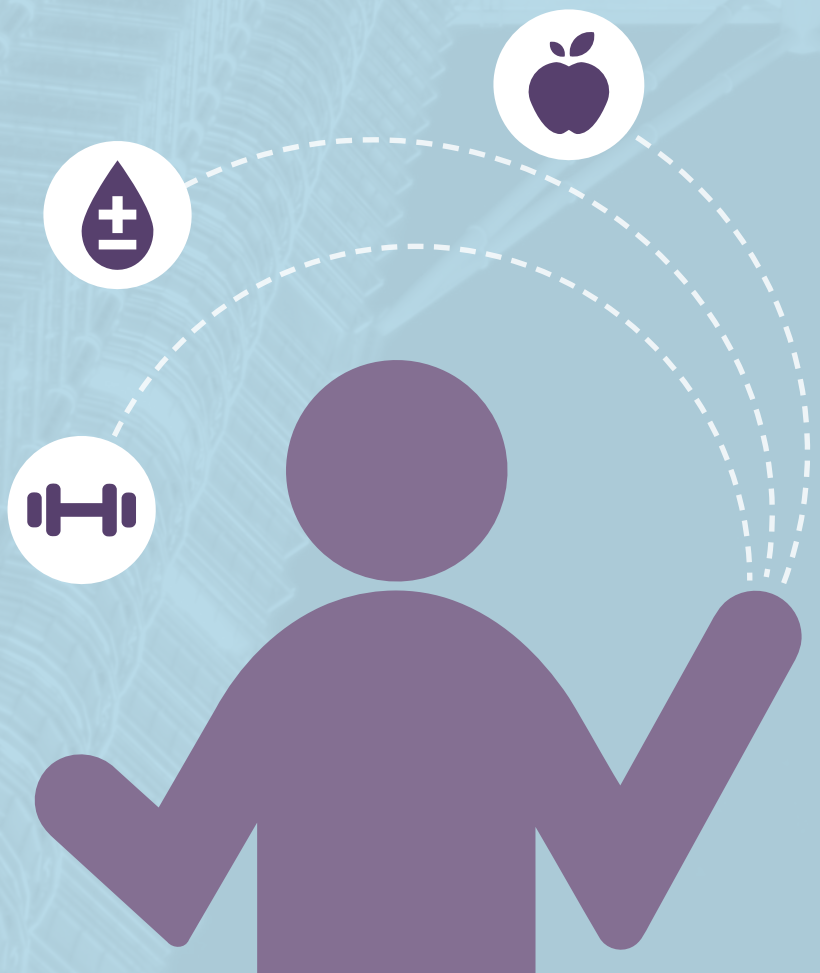
**DME:** Diabetic Macular Edema

[DRBarometer.com](http://DRBarometer.com)



# 13%

of respondents said their vision impairment due to DR or DME made it **difficult to manage their diabetes**





73%

of patients with vision loss due to DR or DME said that their condition made everyday activities, **such as driving**, working and completing basic household tasks difficult and in some cases impossible



13%

of those with DME experienced days of **poor physical and mental health**



27%

of patients either **never discussed eye complications with their doctor** or did so only after the onset of symptoms



8%

of ophthalmologists **had not received specific training** in the treatment and diagnosis of DR and or DME





# Malaysia

## DR Barometer Findings:

### Adults with Diabetes

#### Key Demographic Characteristics

One hundred and ten adults with diabetes (patients) completed the patients' survey in Malaysia: 68% were female and 32% were male. Ninety-four percent lived in an urban setting and 6.5% in a non-urban setting (see Appendix Table 4.2).

The education levels of respondents were as follows: 9.3% did not complete primary school, 26% were educated to a primary school level, 41% to a secondary school level, 16% to a college or university level, and 7.5% to a graduate or post-graduate level (see Appendix Table 4.3).

Twenty-six percent of respondents were in paid employment, 28% were retired, and 38% were not working (see Appendix Table 4.4). Just over half (52%) were aged between 60 and 79 years (5.5% were 18-39 years and 43% were 40-59 years). Forty-eight percent were of traditional working age (18 - 59 years) (see Table 1).

Almost half the respondents in Malaysia (46%) had type 2 diabetes, and only 0.9% had type 1. It was troubling to learn that 53% were either unsure or did not know their type of diabetes (see Appendix Table 2.1). Twenty-eight percent of respondents (n=31) had been diagnosed with DED and a further 8.2% (n=9) with DME.

Most of those surveyed (30%) had been diagnosed with diabetes between 1 and 5 years ago: 6% within the last year, 6 - 10 years ago (24%), 11 - 15 years ago (19%), 16 - 20 years ago (11%), and 21 years ago or more (10%) (see Appendix Table 2.2).

In the subgroup of people aged 18-39 years, 83% had type 2 diabetes, decreasing to 51% in the group aged 40-59 years and 39% in the 60-79 age group.

In the group of respondents aged 18-39 years, 33% had DED and 17% had DME. For those 40-59 years, 28% had DED and 11% had DME, and 28% had DED and 5.3% had DME in the 60-79 year age group.

In those diagnosed with diabetes within the last year, no respondents had DED or DME. Twenty-one percent of those with DED and 9% with DME had been diagnosed 1-5 years ago; and 50% of those diagnosed 21 years ago had DED, and a further 9% had DME.

While two-thirds (67%) of those surveyed reported that their diabetes was well-controlled almost one in three felt that this was not the case. For those who felt their diabetes was controlled, 26% had DED, and 8.3% had DME and where their condition was not well-controlled 33% had DED and 9% had DME.

**Table 1: Summary of key characteristics of adults with diabetes**

Group	Subgroup	All Respondents	Type 1 diabetes	Type 2 diabetes	With DED	With DME
<b>All respondents</b>		110 (100.0%)	1 (0.9%)	51 (46.4%)	31 (28.2%)	9 (8.2%)
<b>Gender</b>	Male	34 (32.1%)	0 (0.0%)	13 (38.2%)	11 (32.4%)	3 (8.8%)
	Female	72 (67.9%)	1 (1.4%)	35 (48.6%)	19 (26.4%)	6 (8.3%)
	Total Missing	4	0	3	1	0
<b>Age</b>	18-39 yrs.	6 (5.5%)	1 (16.7%)	5 (83.3%)	2 (33.3%)	1 (16.7%)
	40-59 yrs.	47 (42.7%)	0 (0.0%)	24 (51.1%)	13 (27.7%)	5 (10.6%)
	60-79 yrs.	57 (51.8%)	0 (0.0%)	22 (38.6%)	16 (28.1%)	3 (5.3%)
<b>Time since diagnosis</b>	Within the last year	6 (5.5%)	1 (16.7%)	4 (66.7%)	0 (0.0%)	0 (0.0%)
	1 - 5 yrs.	33 (30.0%)	0 (0.0%)	16 (48.5%)	7 (21.2%)	3 (9.1%)
	6 - 10 yrs.	26 (23.6%)	0 (0.0%)	10 (38.5%)	4 (15.4%)	3 (11.5%)
	11 - 15 yrs.	21 (19.1%)	0 (0.0%)	7 (33.3%)	9 (42.9%)	0 (0.0%)
	16 - 20 yrs.	12 (10.9%)	0 (0.0%)	7 (58.3%)	5 (41.7%)	1 (8.3%)
	21 yrs. plus	11 (10.0%)	0 (0.0%)	7 (63.6%)	6 (54.5%)	1 (9.1%)
	Don't know/ Not sure	1 (0.9%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (100.0%)
<b>Control of Diabetes</b>	Controlled	72 (66.7%)	1 (1.4%)	25 (34.7%)	19 (26.4%)	6 (8.3%)
	Not controlled	33 (30.6%)	0 (0.0%)	21 (63.6%)	11 (33.3%)	3 (9.1%)
	Don't know/ Not sure	3 (2.8%)	0 (0.0%)	3 (100.0%)	1 (33.3%)	0 (0.0%)
	Total Missing	2	0	2	0	0

NB [1]: Percentages for All Respondents category are calculated based on their respective group. All categories are calculated as row percentages.

NB [2]: Diabetes control is based on the respondents' perception of their own control. Diabetes control terms were grouped as follows; Controlled includes patients who selected 'Very Well' and 'Well'. Not Controlled includes patients who selected 'Not very well' and 'Not well at all'.

NB [3]: DED = respondents with DED = "Yes" minus respondents with DME= "Yes".

NB [4]: DME = respondents with DME = "Yes".

NB [5]: This table is a summary of various questions. For a detailed breakdown for each question, please refer to the Appendices.

## Knowledge and Management of Diabetes

Most (99%) of those surveyed saw a health care professional for their diabetes, with 10% seeing a diabetes specialist (on average 6.4 times per year) and 82% seeing a general or family doctor (on average 3.9 times per year) (see Appendix Table 2.3.1 and 2.3.2).

People were informed about their condition through a variety of channels. Eighty-eight percent received information from a doctor or nurse, 25% from family, friends, or neighbours and 23% from the TV, radio, newspaper or magazines (see Table 2 and Appendix Table 2.4).

**Table 2: Source of information regarding diabetes**

Information Source	All Respondents (n=110)
Doctor or nurse	97 (88.2%)
Family/Friends/Neighbours	27 (24.5%)
TV/Radio/Newspaper/Magazines	25 (22.7%)
Nutritionist or dietician	23 (20.9%)
Health educator	19 (17.3%)
Internet	17 (15.5%)
Diabetes organisation or other health organisation	6 (5.5%)
Social media (e.g. Facebook, Twitter, blogs)	6 (5.5%)
Pharmacist	6 (5.5%)
None of the above	4 (3.6%)

A range of strategies was used by respondents to manage their diabetes. For those with type 1 diabetes, apart from insulin, all respondents managed their diabetes with diet. Of the respondents with type 2 diabetes, 80% managed their condition with oral medicine, 73% with diet, 45% with insulin, 29% with exercise, and 12% with natural or herbal medicine.

Eighteen percent of those surveyed were enrolled in diabetes management programmes and of these 60% said the programme included information on education on the importance of screening for diabetic eye complications (see Appendix Table 2.6).

The nature and frequency of tests that people with diabetes had included blood glucose and eye checks. For those who had eye checks (83%), these occurred at less than 6 months (34%), 6 - 12 months (42%), and greater than 12 months (7.4%) (see Appendix Table 2.7).

The main challenges in controlling diabetes cited by respondents were: that it was too hard to eat the right things (44%), there were long wait times for an appointment to see their doctor or specialist (25%), respondents didn't know enough about their condition (16%), the cost of care was high (12%) and some people didn't want to think about having diabetes (9.2%) (see Appendix Table 2.9).

Free or low cost medicines or monitoring materials (69%), support from family or friends (54%), health education and information (32%), support groups (13%) and coordination of healthcare and services by a professional (11%) were identified as important to improving the management of their diabetes (see Appendix Table 2.10).



## Nature and Information about Complications

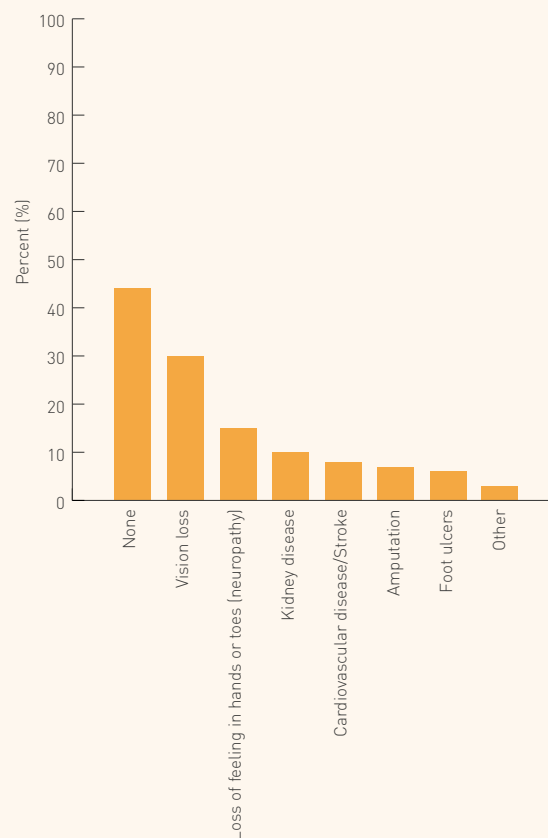
Eighty-four percent of respondents were aware of the complication of vision loss and believed others such as: kidney disease (81%), amputation (76%), foot ulcers (66%), and cardiovascular disease or stroke (64%) were associated with diabetes (see Appendix Table 2.11).

Patients were most concerned about amputation (27%), vision loss (25%), kidney disease (18%), cardiovascular disease or stroke (10%), and foot ulcers (2.8%) (see Appendix Table 2.12).

Forty-four percent had no complications of diabetes however, of those who did have complications, 30% had vision loss, neuropathy (15%), kidney disease (11%), cardiovascular disease or stroke (6.5%) and amputation (5.6%) (see Figure 1 and Appendix Table 2.13).

Most (81%) people with DED and all with DME had complications with their condition (see Table 3 and EXP 1). Aside from vision loss, there was an increase in the frequency of people with DED and DME experiencing certain complications compared to people without DED. The frequency of kidney disease for example increased from 7.4% in those without DED to 19% in DED and 11% in DME. Although the frequency of neuropathy dropped from 12% in those without DED to 9.7% with DED, 56% of those with DME reported neuropathy as a complication.

**Figure 1: Presence of complications**



**Table 3: Presence of complications without DED, with DED or DME**

Complication	Without DED (n=68)	With DED (n=31)	With DME (n=9)
Any	27 (39.7%)	25 (80.6%)	9 (100.0%)
Vision loss	6 (8.8%)	20 (64.5%)	6 (66.7%)
Kidney disease	5 (7.4%)	6 (19.4%)	1 (11.1%)
Loss of feeling in hands or toes (neuropathy)	8 (11.8%)	3 (9.7%)	5 (55.6%)
Amputation	0 (0.0%)	3 (9.7%)	3 (33.3%)
Cardiovascular disease/Stroke	4 (5.9%)	3 (9.7%)	0 (0.0%)
Foot ulcers	4 (5.9%)	0 (0.0%)	1 (11.1%)
Other	1 (1.5%)	0 (0.0%)	1 (11.1%)
None	41 (60.3%)	6 (19.4%)	0 (0.0%)

NB [1]: Without DED = respondents who did not select "Yes" for both DED and DME.

NB [2]: DED = respondents with DED = "Yes" minus respondents with DME = "Yes".

NB [3]: DME = respondents with DME = "Yes".

NB [4]: Percentages within groups are calculated from non-missing data for that question.

NB [5]: Not all responses have been presented in this table, but have been included under "Any". Please see Appendix Table EXP1 for the full list of responses.

## Information about Diabetic Eye Disease and Diabetic Macular Edema

Seventy-six percent of those surveyed said that eye complications were discussed with their health care professionals. Notwithstanding this, nearly one in four (26%) either never discussed them with their health care professionals (19%) or discussions only took place when symptom arose (7%). The frequency of regular discussions varied from every visit (44%), multiple times a year (14%) and once a year (11%) (see Appendix Table 2.14).

Over two-thirds of the patients (68%) reported that they did what they could to prevent vision problems (e.g. get routine screenings, visit specialists), yet 40% thought that vision problems were a normal part of ageing and 10% made no special effort to have a preventative approach to their eye health (see Appendix Table 2.15).

Seventy-five percent of all respondents had received information about DR and DME with the doctor or nurse being the most common source (67%) (see Appendix Table 3.9).

**Table 4: Source of information about DR and DME**

Source	All respondents (n=106)
Doctor/Nurse	71 (67.0%)
TV/Radio/Newspaper/Magazines	19 (17.9%)
Family/Friends/Neighbours	14 (13.2%)
Health educator	11 (10.4%)
Diabetes organisation or other health organisation	7 (6.6%)
Internet	7 (6.6%)
None of the above	26 (24.5%)

NB [1]: Not all respondents answered all questions in the survey; percentages are calculated from non-missing responses to the survey question.

## Screening for Diabetic Eye Disease

Most (88%) respondents reported having an eye exam for DED, with 84% having the exam within the last year and a further 9.5% more than one year ago but less than two years ago. Over a third of respondents were aware of government sponsored screening programmes for DED (see Appendix Table 3.1 and 3.2).

While 79% thought they should have their eyes examined for DED once a year, there were varied smaller numbers of respondents who thought that testing should happen every two years (see Appendix Table 3.4).

The biggest barriers to eye exams were long wait times on the day of the visit (39%), long wait times for an appointment (31%) and the cost of exam was too expensive (8.4%) (see Table 5 and Appendix Table 3.5).

**Table 5: Barriers to eye examinations**

Identified Barriers	All Respondents (n=107)
Long wait time on the day of the visit	42 (39.3%)
Long wait time for appointment	33 (30.8%)
They are expensive	9 (8.4%)
Eye exams are not available near my home	9 (8.4%)
Burden on my family/friends	9 (8.4%)
Referral process is complicated or takes too long	8 (7.5%)
Don't know much about my condition	8 (7.5%)
Recommended treatments for eye problems are not available	6 (5.6%)
Fear of treatment/results	5 (4.7%)
Limited access to diabetes specialists	5 (4.7%)
Too many other things to do or worry about	4 (3.7%)
I'm not likely to have eye complications	3 (2.8%)
Clinics are too small or lack necessary equipment/staff	2 (1.9%)
Eye exams are not important	1 (0.9%)
Other	34 (31.8%)



## Treatment of Diabetic Eye Disease and Diabetic Macular Edema

Treatment was assessed separately in people with DED and in those with DME. Those with DED (68%) received treatment with the most common treatment being laser (85%) which was on going for 15%. Over three-quarters had completed treatment and 80% felt it had been successful and their vision either had improved (65%) or had stayed the same (15%) (see Table 6).

For the nine respondents (29%) with DED who had not received treatment, the most common reason reported was that their doctor did not recommend treatment.

Eighty-eight percent of those with DME (n=7) received treatment with the most common treatment being laser and anti-VEGF therapy, and most felt that it had been successful and either their vision had improved (43%) or stayed the same (43%).

There was a strong preference by all those with DME to have a proactive approach in the treatment pathway to prevent further vision loss rather than a reactive approach once further vision loss occurred (see Appendix Table 3.8).

**Table 6: Treatment characteristics of patients with DED and DME**

Question	Response	With DED (n=31)	With DME (n=8)
Have you had any treatment for diabetic eye disease?	Yes	21 (67.7%)	7 (87.5%)
	No	9 (29.0%)	1 (12.5%)
	Don't know/Not sure	1 (3.2%)	0 (0.0%)
What treatment did you receive?	Laser	17 (85.0%)	7 (100.0%)
	Anti-VEGF	2 (10.0%)	3 (42.9%)
	Surgery	1 (5.0%)	0 (0.0%)
	Other	2 (10.0%)	0 (0.0%)
Did you complete the treatment?	Yes	16 (80.0%)	6 (85.7%)
	Still receiving treatment	3 (15.0%)	1 (14.3%)
	Don't know/Not sure	1 (5.0%)	0 (0.0%)
Do you feel that the treatment worked?	Yes, and vision improved	13 (65.0%)	3 (42.9%)
	Yes, but vision stayed the same	3 (15.0%)	3 (42.9%)
	No	1 (5.0%)	1 (14.3%)
	Still waiting to know	2 (10.0%)	0 (0.0%)
	Don't know/Not sure	1 (5.0%)	0 (0.0%)
What are the reason(s) that you have not had treatment for diabetic eye disease?	My doctor did not recommend any treatment	8 (88.9%)	1 (100.0%)
	Other	1 (11.1%)	0 (0.0%)

NB [1]: DED = respondents with DED = "Yes" minus respondents with DME = "Yes".

NB [2]: DME = respondents with DME = "Yes".

NB [3]: Not all respondents answered all questions in the survey; percentages are calculated from non-missing responses to the survey question.

NB [4]: This table is a summary of various questions. For a detailed breakdown for each question, please refer to the Appendices.

## Impact of Diabetic Eye Disease and Diabetic Macular Edema

Eighty percent of those diagnosed with DED or DME said that their vision was affected (36% significantly, 44% slightly) (see Appendix Table 3.6).

Seventy-three percent of this subgroup said that the vision issues impacted their daily lives in various ways such as difficulty in travelling (50%), driving a vehicle (30%), undertaking household responsibilities, such as cooking or cleaning (27%), social interactions with family and friends (27%), leisure activities or exercise (20%), working or keeping a job (17%), and managing their underlying diabetes (13%) (see Table 7).

**Table 7: Activities affected through vision impairment and loss**

	<b>All Respondents (n=30)</b>
Travelling	15 (50.0%)
Driving (a car/vehicle)	9 (30.0%)
Household responsibilities, such as cooking or cleaning	8 (26.7%)
Social interactions with family/friends	8 (26.7%)
Leisure activities/exercise	6 (20.0%)
Work or keeping a job	5 (16.7%)
Managing my diabetes	4 (13.3%)
Other	1 (3.3%)
None	8 (26.7%)

Seventeen percent of those with DED and 44% with DME were in paid employment compared with 28% of respondents without DED (see Table 8 and EXP 5.1). Some patients with vision complications reported difficulties with work or keeping a job (17%) and 53% of those with DED were not working.

Forty-eight percent did not receive assistance from the government while 26% received medical assistance (see Appendix Table 4.5). The presence of eye complications was not necessarily associated with the receipt of government assistance as the study showed that 47% of those without DED did in fact receive assistance. However, those with DME (78%) and DED (57%) may be more likely to receive government assistance.

Most (91%) of respondents said they had no trouble paying for food at any time during the past year and 79% didn't feel that their access to health care was affected by any factors. A small percentage of respondents (10%) felt that their access was affected by age. Fifty-four percent of respondents were worried about their health, 2.8% about family while 27% were not worried about any of the items in the survey (see Appendix Table 4.6, 4.7 and 4.8).

**Table 8: Socio-economic profile of patients without DED, with DED or DME**

Question	Response	Without DED (n=68)	With DED (n=30)	With DME (n=9)
Are you currently working?	Working for pay	19 (27.9%)	5 (16.7%)	4 (44.4%)
	Working without pay at home (e.g. housework, farming)	5 (7.4%)	2 (6.7%)	1 (11.1%)
	Retired	21 (30.9%)	7 (23.3%)	2 (22.2%)
	Not working	23 (33.8%)	16 (53.3%)	2 (22.2%)
Question	Response	Without DED (n=66)	With DED (n=28)	With DME (n=9)
Do you receive assistance from the government?	Income assistance	4 (6.1%)	4 (14.3%)	5 (55.6%)
	Medical assistance	16 (24.2%)	11 (39.3%)	0 (0.0%)
	Housing assistance	0 (0.0%)	0 (0.0%)	1 (11.1%)
	Pension assistance	14 (21.2%)	5 (17.9%)	1 (11.1%)
	None of the above	35 (53.0%)	12 (42.9%)	2 (22.2%)
Question	Response	Without DED (n=65)	With DED (n=30)	With DME (n=9)
Did you have trouble paying for food at any time during the past year?	Yes	6 (9.2%)	1 (3.3%)	2 (22.2%)
	No	59 (90.8%)	29 (96.7%)	7 (77.8%)

NB [1]: Without DED = respondents who did not select "Yes" for both DED and DME.

NB [2]: DED = respondents with DED = "Yes" minus respondents with DME = "Yes".

NB [3]: DME = respondents with DME = "Yes".

NB [4]: Not all respondents answered all questions in the survey; percentages are calculated from non-missing responses to the survey question.

NB [5]: This table is a summary of various questions. For a detailed breakdown for each question, please refer to the Appendices.

## Self-reported Quality of Life

The CDC HRQOL-4 Core Modules of the “Healthy Days Measure” was used to capture information on self-reported quality of life, based on the number of unhealthy days within the last 30 days from when the survey was taken. The reported health status varied depending on whether respondents had been diagnosed with DED or DME (see Table 9).

The presence or not of DED was not associated to whether health was reported to be poor or good. Of those without DED, 51% reported good self-rated health (60% with DED, 56% with DME) and 49% reported poor self-rated health (40% with DED, 44% with DME). These findings could be explained by the impact of other complications experienced by those without DED.

Even though reported health was reasonably consistent whether the respondent had DED or not, there was a 21% increase in the activity limitation days between those without DED and those with DME.

**Table 9: Self-reported healthy days of patients without DED, with DED or DME**

Health Status	Without DED	With DED	With DME
Self-rated health: Good	34 (50.7%)	18 (60.0%)	5 (55.6%)
Self-rated health: Poor	33 (49.3%)	12 (40.0%)	4 (44.4%)
Physically unhealthy days	9 (15.8%)	4 (16.7%)	0 (0.0%)
Mentally unhealthy days	3 (5.1%)	2 (7.4%)	1 (11.1%)
Unhealthy days	9 (16.4%)	4 (16.7%)	1 (12.5%)
Activity limitation days	5 (29.4%)	1 (16.7%)	1 (50.0%)

NB [1]: Without DED = respondents who did not select “Yes” for both DED and DME.

NB [2]: DED = respondents with DED = “Yes” minus respondents with DME = “Yes”.

NB [3]: DME = respondents with DME = “Yes”.

NB [4]: Not all respondents answered all questions in the survey; percentages are calculated from non-missing responses to the survey question.

NB [5]: This table is a summary of various questions. For a detailed breakdown for each question, please refer to the Appendices.

# Malaysia

## DR Barometer Findings:

### Health Care Professionals

#### Key Demographic Characteristics

There were 50 health care professionals who answered at least one of the survey questions in Malaysia. Of these, eight were primary care providers (16%), five were diabetes specialist providers (10%) and 15 were ophthalmologists (30%). The remaining respondents were optometrists, nurses, health educators or other professionals (see Appendix PT 1.3).

In this section of the report, data from health care professionals as a whole and then the ophthalmologist subgroup will be reported.

Health care professionals and ophthalmologists as groups had been practicing for an average of 13 years (see Appendix PT 1.5). All were well educated (81% with graduate or advanced degree); 63% were female and 38% male; and, 56% were aged 40-49 years with a further 28% in the 30-39 age groups (see Table 10 and Appendix PT 3.1).

**Table 10: Summary of key characteristics of health care professionals**

Group	Subgroup	All Respondents	Primary Care Provider	Diabetes Specialist	Ophthalmologist
<b>All respondents</b>		50 (100.0%)	8 (16.0%)	5 (10.0%)	15 (30.0%)
<b>Age group</b>	18 - 29 yrs.	2 (6.3%)	1 (20.0%)	0 (0.0%)	0 (0.0%)
	30 - 39 yrs.	9 (28.1%)	1 (20.0%)	2 (50.0%)	2 (16.7%)
	40 - 49 yrs.	18 (56.3%)	2 (40.0%)	2 (50.0%)	9 (75.0%)
	50 - 59 yrs.	1 (3.1%)	0 (0.0%)	0 (0.0%)	1 (8.3%)
	60 - 69 yrs.	2 (6.3%)	1 (20.0%)	0 (0.0%)	0 (0.0%)
<b>Gender</b>	Female	20 (62.5%)	3 (60.0%)	2 (50.0%)	7 (58.3%)
	Male	12 (37.5%)	2 (40.0%)	2 (50.0%)	5 (41.7%)
<b>Education</b>	College/University	6 (18.8%)	0 (0.0%)	1 (25.0%)	0 (0.0%)
	Graduate or advanced degree (e.g. PhD, MD, etc.)	26 (81.3%)	5 (100.0%)	3 (75.0%)	12 (100.0%)

NB [1]: This table is a summary of various questions. For a detailed breakdown for each question, please refer to the Appendices.



## Clinical Practice Characteristics

Thirty-one percent of all providers had their main practice setting in a hospital and for ophthalmologists only the settings were hospital (53%), and eye clinic (47%). Eighty-three percent of health care professionals worked in an urban setting (see Appendix PT 2.1 and PT 2.2).

Most health care professionals worked in the private sector (50%) and ophthalmologists worked mainly in private (53%), government (33%), and combined or mixed (13%) sector (see Appendix PT 2.3).

Providers overall said that 37% of patients pay a reduced or subsidised rate for services, 37% pay out-of-pocket (full fees) and 27% pay through insurance. The pattern was similar for ophthalmologists, where 50% of patients pay a reduced or subsidised rate for services, 29% of patients pay out-of-pocket (full fees) and 29% pay through insurance (see Appendix PT 2.7).

Providers saw 92 patients per week with 48% (on average) having diabetes while ophthalmologists reported seeing an average 82 patients per week with 40% of patient with diabetes (see Appendix PT 2.6).

For all health care professionals (and ophthalmologists) respectively the average waiting time for an appointment was most commonly less than one week (24% vs 36%), or between one and two months (22% vs 29%) (see Appendix PT 2.5).

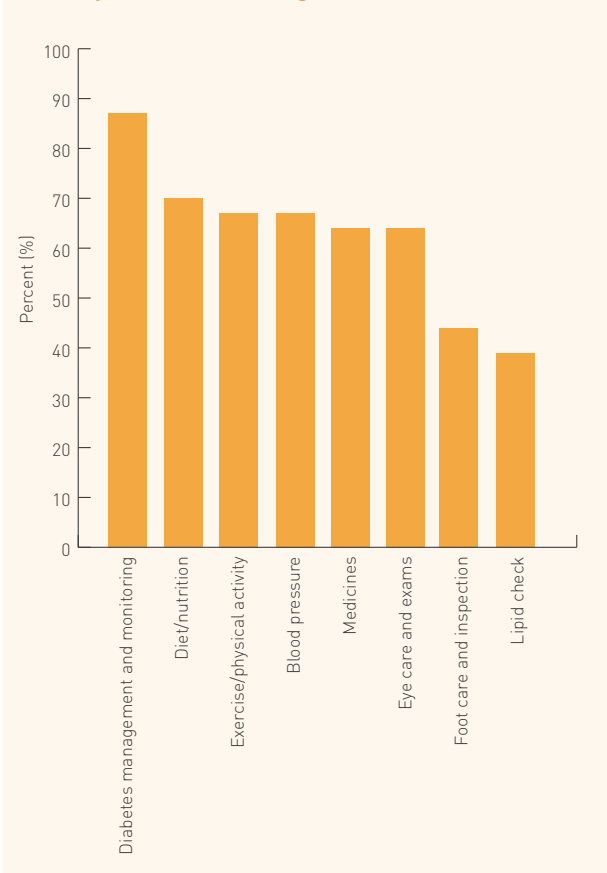
**Table 11: Average wait times to schedule an appointment**

Wait Time Intervals	All Respondents (n=41)	Ophthalmologist (n=14)
Less than 1 week	10 (24.4%)	5 (35.7%)
More than 1 week but less than 1 month	7 (17.1%)	3 (21.4%)
More than 1 month but less than 2 months	9 (22.0%)	4 (28.6%)
More than 2 months but less than 3 months	6 (14.6%)	1 (7.1%)
More than 3 months but less than 6 months	2 (4.9%)	0 (0.0%)
Do not take appointments	4 (9.8%)	1 (7.1%)
Other	2 (4.9%)	0 (0.0%)
Don't know/Not sure	1 (2.4%)	0 (0.0%)

### Patient Education Information

A wide range of topics related to diabetes and its management were addressed by the health care professionals in a routine visit (see Figure 2 and Appendix PT 2.10).

**Figure 2: Health care topics discussed with patients during a routine visit**



Health care professionals stated that written information about diabetes is available, yet the adequacy of that related to eye complications varies.

Thirty-one percent of all providers reported that they had sufficient information about eye complications, yet 49% had information but that which was on eye complications was insufficient. Overall 20% of those surveyed had no written information (see Table 12 and Appendix PT 2.11).

Some ophthalmologists (42%) had written information about diabetes and potential eye complications, yet 25% had information on diabetes but information on eye complications was not sufficient. Thirty-three percent of ophthalmologists said there was no written information available at all.

## Guidelines and Protocols

Sixty-three percent of providers and 42% of ophthalmologists had written protocols for the management of diabetes, which were used by staff. However, 26% had no protocols (see Appendix PT 2.12).

With respect to the management of diabetes-related vision issues, only 44% of health care professionals and 33% of ophthalmologists had written protocols, which were used by staff but for some 12% the protocols available were not used by staff. Thirty-five percent of providers did not have protocols on the management of diabetes-related vision issues available (see Table 12 and Appendix PT 2.13).

**Table 12: Availability and use of information and protocols**

Question	Response	All Respondents (n=35)	Ophthalmologist (n=12)
Is there written information about diabetes available for patients in your main practice?	Yes, and information on eye complications is sufficient	11 (31.4%)	5 (41.7%)
	Yes, but information on eye complications is not sufficient	17 (48.6%)	3 (25.0%)
	No written information is available for patients	7 (20.0%)	4 (33.3%)
Question	Response	All Respondents (n=50)	Ophthalmologist (n=16)
Do you have written protocols/guidelines for detection and management of diabetes-related vision issue available in your main practice?	Yes, available and used by staff	15 (44.1%)	4 (33.3%)
	Yes, available but not used by staff	4 (11.8%)	2 (16.7%)
	Not available	12 (35.3%)	5 (41.7%)
	Don't know/Not sure	3 (8.8%)	1 (8.3%)

NB [1]: This table is a summary of various questions. For a detailed breakdown for each question, please refer to the Appendices.

## Screening Protocols and Barriers in the Care Pathway

Timing for the initial eye exam for persons with diabetes varied depending upon the type of diabetes as reported by all providers. Thirty percent of providers reported that an initial eye exam should occur at time of the diagnosis of type 1 diabetes and 66% in regards to type 2 diabetes (75%) (see Appendix PT 2.14).

Overall, 77% of health care professionals and 83% of ophthalmologists said that follow-up eye examinations should be annual and most (all ophthalmologists, 89% of all providers) said they screen patients for DR (see Appendix PT 2.15 and PT 2.16).

Across all health care professionals, 47% send appointment reminders while 47% do not (see Appendix PT 2.19). About three-quarters of the health care professionals and ophthalmologists shared information to optimise patient care management (see Appendix PT 2.20).

The most common patient characteristics influencing the referral process for eye complications for all health professionals were: the duration of diabetes (94%), high glucose levels (88%), and presence of comorbidities such as hypertension (75%) (see Appendix PT 2.17).

The major barriers to optimising eye health faced by patients with diabetes according to providers were a lack of knowledge and/or awareness (72%), patients feeling that eye exams were not important (69%) and the patient's fear of the treatment and/or the results (59%). Ophthalmologists like health care professionals reported similar such barriers (see Table 13 and Appendix PT 2.18).

**Table 13: Major barriers to optimising eye health**

<b>Response</b>	<b>All Respondents (n=32)</b>	<b>Ophthalmologists (n=12)</b>
Patients feel eye exams are not important	22 (68.8%)	12 (100.0%)
Lack of knowledge and/or awareness	23 (71.9%)	11 (91.7%)
Patients fear of treatment/results	19 (59.4%)	8 (66.7%)
Patients feel eye complications are unlikely	17 (53.1%)	8 (66.7%)
Cost of care	18 (56.3%)	6 (50.0%)
Proximity to care	13 (40.6%)	6 (50.0%)
Patients have competing responsibilities and priorities	16 (50.0%)	6 (50.0%)
Referral process	11 (34.4%)	5 (41.7%)
Limited access to eye specialists	10 (31.3%)	4 (33.3%)
Recommended treatments are not available	7 (21.9%)	3 (25.0%)
Patients feel they are a burden on family/friends	6 (18.8%)	3 (25.0%)
Long wait time for appointment	11 (34.4%)	2 (16.7%)
Long wait time on the day of visit	13 (40.6%)	2 (16.7%)
Limited access to diabetes specialists	6 (18.8%)	2 (16.7%)
Clinic too small or lack necessary equipment/staff	5 (15.6%)	0 (0.0%)
Other	1 (3.1%)	0 (0.0%)



# Malaysia

## DR Barometer Findings:

### Ophthalmologists

#### Screening

There were twelve ophthalmologists who answered at least one of the supplementary questions (see Appendix PT 4.1 to PT 4.14). On average 42% of patients seen by the ophthalmologists had DR and 26% DME (see Appendix PT 4.1 and PT 4.2).

The most common waiting time for a screening appointment for DED was less than one week (42%) with 17% stating more between one week and a month (see Appendix PT 4.3).

#### Treatment and Challenges

All ophthalmologists personally administer treatment for DR and the most common factors influencing treatment was the presence of comorbidities such as hypertension (50%), the duration of diabetes (42%) and high glucose levels (42%) (see Appendix PT 4.6 and PT 4.7).

The most common venues for outreach for screening for DED were health fairs for all (42%), health fairs for people with diabetes (42%), vision centres (42%), and mobile screening centres (33%) (see Appendix PT 4.13).

Three-quarters of ophthalmologists screen patients for DR based on fundoscopy through dilated pupils. Additionally, 67% used a retinal photo, 58% base their decisions on optical coherence tomography and 25% on fundoscopy through undilated pupils. Sixty-seven percent treat DR and DME based on both visual and anatomical outcomes (see Appendix PT 4.8 and PT 4.9).

Seventy-five percent (n=9) said that most patients present when visual problems have already occurred while the remainder said that patients present in time for screening although the sample is notably very small (see Appendix PT 4.10).

Ninety-two percent of ophthalmologists had received specific training on the treatment and diagnosis of DR and or DME. For 46% training was between one and five years ago, for 27% it was five years ago or more, and for 27% training was within the past year. Most (83%) would be interested in online education and certification on DME, angiogenesis, and anti-VEGF therapies (see Appendix PT 4.11 and PT 4.12).

Ophthalmologists said that the greatest challenges for improving patient outcomes in DED were limited access to patient education on DR and DME (75%, n=9), and late diagnosis (67%, n=8) (see Table 14 and Appendix PT 4.14).

**Table 14: Challenges for improving outcomes in DED**

Question	Response	Ophthalmologist (n=12)
What do you perceive to be the greatest challenges for improving patient outcomes in diabetic eye disease?	Limited access to patient education on diabetic retinopathy and diabetic macular edema	9 (75.0%)
	Late diagnosis	8 (66.7%)
	Ineffective screening services	6 (50.0%)
	Reimbursement/restrictions on approved therapy	5 (41.7%)
	Referral pathways	5 (41.7%)
	Government/insurance not able to cover patient costs	5 (41.7%)
	Multi-disciplinary team integration is poor	3 (25.0%)

# Malaysia

## DR Barometer Summary

In Malaysia, 110 adults with diabetes and 50 health care professionals provide insight about their experiences of living with, managing and treating diabetes, DR and DME.

The results of the DR Barometer Study, Malaysia were intended to improve the level of awareness around diabetes and eye complications, and access and barriers to diabetes management, including screening for DED and DME and timely treatment.

Malaysia will reach a significant demographic milestone. By 2050, the population will have increased by 34% with a demographic shift, which will be historically unprecedented. In just 34 years, the population of older people will reach an all-time high of 9.7 million representing about 24% of the total population, which is a tremendous increase in this cohort compared with a 9% decrease of those aged 14 years or younger.

Alongside the demographic changes, the prevalence of people with diabetes in Malaysia is climbing rapidly and has the eighth highest number of people living with diabetes in the Western Pacific region at ~3.3 million (2,969.0-3,801.9†). The diabetes national prevalence in Malaysia (20 – 79 years) is 16.6% (14.9-19.1†), which is well above the global average of 8.8%.

Deaths attributed to diabetes in Malaysia in 2015 were 34,576, which accounts for ~3% of the diabetes related deaths experienced in this region. The estimated number of undiagnosed cases was 1.7 million (1,538.5-1,970.2†).

Almost half the respondents in Malaysia (46%) had type 2 diabetes, with only 0.9% with type 1. A concerning finding was that 53% were either unsure or did not know their type of diabetes.

The DR Barometer findings indicate that overall a younger population was more

likely to be associated with type 1 diabetes, which was the opposite for those with type 2 diabetes, which tended to be an older population. While it is difficult to substantiate this trend with the findings in Malaysia, due to the high percentage of respondents who were unaware which type of diabetes they had and only one respondent reported having Type 1, there was a general decrease in the percentage of adult with type 2 diabetes with increasing age. In the subgroup of people aged 18-39 years, 83% had type 2 diabetes, decreasing to 51% for those aged 40-59 years and 39% in the 60-79 age group.

People were almost solely informed about their condition by health professionals such as the doctor and nurse. Family and friends, TV, newspapers, radio and magazines as well as the nutritionist were noted as sources of information by a much lower proportion of respondents.

Only 18% of respondents were enrolled in diabetes management programmes and most (60%) noted there was education on the importance of screening for eye complications.

Many of those surveyed struggled with the management of their diabetic condition with some issues that were within their personal control such as eating the right foods. In addition, long wait times for appointments, the high cost of care and not knowing enough about their condition were seen as challenges.

There was a relatively high awareness of the complications associated with diabetes. Amputations (27%) and vision loss (25%) were most concerning followed by kidney disease and cardiovascular disease. While 44% of those surveyed had no complications there were still many who reported having vision loss, neuropathy, and kidney disease. While the number of respondents was small, 81% of those with DED and DME had complications with an increase in frequency for certain conditions such as kidney disease

and neuropathy. Notable the sample size is very small so it is not possible to determine whether this is a trend.

Knowing that diabetic-related vision loss is preventable addressing barriers to eye screening is an important policy issue. While most respondents had received an eye exam, which is understandable considering the purposeful sample, there remained many barriers including long wait times for an appointment and also on the day, and the high cost of the exam.

Evidence shows that the relationship between the patient and the health care professional is critical to ensure realistic and optimal patient outcomes. It was therefore surprising that nearly a quarter of patients surveyed had either never had a conversation about eye complications with their health professional or it only took place only when symptoms were present. Equally concerning is the myths and perceptions around vision changes with more than 15% of patients reporting that vision problems were a normal part of ageing and some not making any special effort to prevent vision problems.

Eighty percent of those with DED or DME said that their vision was slightly or significantly affected which in turn impacted their health, lifestyle, and life choices including difficulty in travelling, driving a vehicle, undertaking household responsibilities, such as cooking or cleaning and social interactions with family and friends.

A proactive treatment approach to prevent further vision loss was preferred rather than reactive treatment once further vision loss had occurred. However, for some (10%) respondents, access to healthcare was affected by their age.

Patient education is very much at the heart of a proactive approach so it was somewhat unexpected to find that 49% of providers

said that the written information diabetes and eye complications available was not sufficient, and 20% didn't have information. Furthermore, only 44% of providers, including 33% of ophthalmologists, had written protocols for the detection and management of diabetes-related vision issues that were used by staff. It is noteworthy that 35% of providers did not have protocols on the management of diabetes-related vision.

For both patients with either type 1 or type 2 diabetes 66% and 75% of all providers respectively said that an initial eye exam should occur at time of the diagnosis of diabetes and there was agreement by most providers and ophthalmologists that follow-up eye examinations should be conducted every year.

The top three patient characteristics influencing the referral process for eye complications across providers and ophthalmologists were the duration of diabetes, high glucose levels, and the presence of comorbidities such as hypertension.

Limited access to patient education and late diagnosis were viewed by ophthalmologists as some of the greatest challenges for improving patient outcomes in DED.

In large part, the patients and providers who participated in the study were self-selected, and therefore this population group is more likely to be engaged and motivated in the management of their diabetes hence a possible explanation for the rates of awareness and screening.

Even though the sample is not representative of the broader population, and as such may not truly reflect the national situation, the findings illustrate important trends, and certainly highlight specific areas of concern and potential calls for policy action in Malaysia.



# References and Acknowledgement

<sup>1</sup> The World Bank. (2016). *Health nutrition and population statistics: Population estimates and projections* (World Data Bank). Washington, D.C.: The World Bank. Retrieved from <http://databank.worldbank.org/data/reports.aspx?source=Health%20Nutrition%20and%20Population%20Statistics:%20Population%20estimates%20and%20projections>

<sup>2</sup> Department of Economic and Social Affairs. (2016). *World Population Prospects* (No. ESA/P/WP.241). United Nations. Retrieved from [https://esa.un.org/unpd/wpp/publications/files/key\\_findings\\_wpp\\_2015.pdf](https://esa.un.org/unpd/wpp/publications/files/key_findings_wpp_2015.pdf)

<sup>3</sup> International Diabetes Federation. (2015). *IDF Diabetes Atlas*. Accessed from: <http://www.diabetesatlas.org/>

The IFA, IDF and IAPB would like to acknowledge and thank the many organisations and health care professionals from Malaysia that assisted in the dissemination of patient and provider surveys, your contributions were pivotal to the success of the DR Barometer Study.

# Appendices

# The Diabetic Retinopathy Barometer Survey: Appendices for Malaysia

## APPENDIX 1 : National Results

**Table 1.1**

Survey Information	Number of Respondents (%)
All valid respondents [1]	117 (100.0%)
Respondents aged 18 or over	117 (100.0%)
Respondents with diabetes	112 (95.7%)

*NB [1]: valid respondents are those with country information*

**Table 1.2**

Survey Information	Number of Respondents (%)
All valid respondents	117 (100.0%)
Included in Diabetic Analysis Set	110 (94.0%)
Excluded from Diabetic Analysis Set	7 (6.0%)
Reasons for exclusion from diabetic analysis set	.
Not diagnosed with diabetes	4
Missing information on diabetes diagnosis	1
Gestational diabetes only	2

**Table 1.3**

Survey Information	Number of Respondents (%)
Diabetic Analysis Set	110 (100.0%)
World Bank Income Group: Upper-middle income	110 (100.0%)
Persons with diabetic eye disease (DED)	31 (28.2%)
Persons with diabetic macular edema (DME)	9 (8.2%)
Persons with Type I diabetes	1 (0.9%)
Persons with Type II diabetes	51 (46.4%)
Persons not seeing health care professional for diabetes	1 (0.9%)
Persons seeing health care professional for diabetes	109 (99.1%)
Persons with eye disease & not received treatment	10 (9.1%)
Persons with eye disease & received treatment	28 (25.5%)

**Table 2.1**

Question	Response	Number of Respondents (%)
With which type of diabetes have you been diagnosed?	Type I	1 (0.9)
	Type II	51 (46.4)
	Don't know/Not sure	58 (52.7)
	Total Valid Response	110 (100.0)

**Table 2.2**

Question	Response	Number of Respondents (%)
When was your diabetes diagnosed?	Within the last year	6 (5.5)
	1 - 5 years ago	33 (30.0)
	6 - 10 years ago	26 (23.6)
	11 - 15 years ago	21 (19.1)
	16 - 20 years ago	12 (10.9)
	21 years ago or longer	11 (10.0)
	Don't know/Not sure	1 (0.9)
	Total Valid Response	110 (100.0)

**Table 2.3.1**

Question	Response	Number of Respondents (%)
Do you see a health care professional for your diabetes?	Yes	109 (99.1)
	No	1 (0.9)
	Total Valid Response	110 (100.0)
What kind of health care professional?	General/Family Doctor	89 (82.4)
	Nurse	6 (5.6)
	Diabetes Specialist	11 (10.2)
	Other	1 (0.9)
	Don't know/Not sure of kind	1 (0.9)
	Total Valid Response	108 (100.0)



Question	Response	Number of Respondents (%)
	Total missing	2

**Table 2.3.2**

Type of health care professional	Times per year seen for diabetes	Value
General/Family Doctor	Total valid numeric response (n)	85
	Mean	3.9
	SD	2.2
	Median	4.0
	Min	2
	Max	20
	Don't know/Not sure	2
	Total missing	2
Nurse	Total valid numeric response (n)	6
	Mean	4.5
	SD	2.0
	Median	4.0
	Min	2
	Max	8
Diabetes Specialist	Total valid numeric response (n)	10
	Mean	6.4
	SD	4.1
	Median	5.0
	Min	2
	Max	12
	Total missing	1
Other	Total valid numeric response (n)	1
	Mean	2.0
	SD	
	Median	2.0
	Min	2
	Max	2
Don't know/Not sure of kind	Total valid numeric response (n)	1
	Mean	4.0

Type of health care professional	Times per year seen for diabetes	Value
	SD	
	Median	4.0
	Min	4
	Max	4

**Table 2.4**

Question	Response	Number of Respondents (%)
How have you received information about diabetes?	Doctor or nurse	97 (88.2%)
	Health educator	19 (17.3%)
	Nutritionist or dietitian	23 (20.9%)
	Diabetes organization or other health organization	6 (5.5%)
	Family/Friends/Neighbors	27 (24.5%)
	TV/Radio/Newspaper/Magazines	25 (22.7%)
	Internet	17 (15.5%)
	Social media (e.g. Facebook, Twitter, blogs)	6 (5.5%)
	Pharmacist	6 (5.5%)
	None of the above	4 (3.6%)
	Total Valid Response	110 (100.0%)

**Table 2.5**

Question	Response	Number of Respondents (%)
How do you manage your diabetes?	Diet	73 (67.0%)
	Oral medicine	90 (82.6%)
	Exercise	25 (22.9%)
	Insulin	45 (41.3%)
	Natural/Herbal medicine	8 (7.3%)
	Total Valid Response	109 (100.0%)
	Total missing	1

**Table 2.6**

Question	Response	Number of Respondents (%)
Are you currently enrolled in a diabetes patient management support programme?	Yes	20 (18.2)
	No	90 (81.8)
	Total Valid Response	110 (100.0)
Who sponsors the programme?	Hospital support program	14 (73.7)
	Clinic support program	3 (15.8)
	Patient organization support program	1 (5.3)
	Don't know/Not sure	1 (5.3)
	Total Valid Response	19 (100.0)
	Total missing	91
Does the programme include education on the importance of screening for diabetic eye complications?	Yes	12 (60.0)
	No	8 (40.0)
	Total Valid Response	20 (100.0)
	Total missing	90

**Table 2.7**

Test	Response	Number of Respondents (%)
Have you ever had the following tests in a doctor's office or clinic?		
Blood glucose test	Yes	109 (100.0%)
	Less than 6 months	98 (89.9%)
	6 - 12 months	8 (7.3%)
	Greater than 12 months	2 (1.8%)
	Total valid response	108 (99.1%)
	Total missing	2
	Total valid response	109 (100.0%)
	Total missing	1

Test	Response	Number of Respondents (%)
Urine check	Yes	101 (93.5%)
	Less than 6 months	91 (84.3%)
	6 - 12 months	6 (5.6%)
	Greater than 12 months	3 (2.8%)
	Total valid response	100 (92.6%)
	Total missing	10
	No	7 (6.5%)
	Total valid response	108 (100.0%)
	Total missing	2
Weight check	Yes	102 (93.6%)
	Less than 6 months	92 (84.4%)
	6 - 12 months	7 (6.4%)
	Greater than 12 months	2 (1.8%)
	Total valid response	101 (92.7%)
	Total missing	9
	No	7 (6.4%)
	Total valid response	109 (100.0%)
	Total missing	1
Blood pressure check	Yes	107 (98.2%)
	Less than 6 months	95 (87.2%)
	6 - 12 months	8 (7.3%)
	Greater than 12 months	2 (1.8%)
	Total valid response	105 (96.3%)
	Total missing	5
	No	1 (0.9%)

Test	Response	Number of Respondents (%)
	Don't know/Not sure	1 (0.9%)
	Total valid response	109 (100.0%)
	Total missing	1
Foot check	Yes	79 (73.1%)
	Less than 6 months	72 (66.7%)
	6 - 12 months	3 (2.8%)
	Greater than 12 months	3 (2.8%)
	Total valid response	78 (72.2%)
	Total missing	32
	No	29 (26.9%)
	Total valid response	108 (100.0%)
	Total missing	2
Eye check	Yes	90 (83.3%)
	Less than 6 months	37 (34.3%)
	6 - 12 months	45 (41.7%)
	Greater than 12 months	8 (7.4%)
	Total valid response	90 (83.3%)
	Total missing	20
	No	17 (15.7%)
	Don't know/Not sure	1 (0.9%)
	Total valid response	108 (100.0%)
	Total missing	2

**Table 2.8**

Question	Response	Number of Respondents (%)
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Question	Response	Number of Respondents (%)
How well do you think your diabetes is controlled?	Very well	7 (6.5%)
	Well	65 (60.2%)
	Not very well	31 (28.7%)
	Not well at all	2 (1.9%)
	Don't know/Not sure	3 (2.8%)
	Total Valid Response	108 (100.0%)
	Total missing	2

**Table 2.9**

Question	Response	Number of Respondents (%)
What are the main challenges you face in controlling your diabetes?	High cost of care	13 (11.9%)
	No insurance	4 (3.7%)
	Travel to my regular doctor or specialist is difficult	9 (8.3%)
	Long wait time for an appointment to see my doctor or specialist	27 (24.8%)
	Health services needed are not available	6 (5.5%)
	Don't know enough about diabetes	17 (15.6%)
	Too hard to eat the right things	48 (44.0%)
	Too many other things to do	8 (7.3%)
	Stigma or discrimination because of diabetes	2 (1.8%)
	Don't want to think about having diabetes	10 (9.2%)
	Other	1 (0.9%)
	Total Valid Response	109 (100.0%)
	Total missing	1

**Table 2.10**



Question	Response	Number of Respondents (%)
Which of the following services currently help you better manage your diabetes?	Free or low cost medicines or monitoring materials	74 (68.5%)
	Support groups	14 (13.0%)
	Support from family or friends	58 (53.7%)
	Health education and information	35 (32.4%)
	Mobile services (services that travel to or near your home)	4 (3.7%)
	Coordination of healthcare and services by a professional	12 (11.1%)
	Emergency helpline	3 (2.8%)
	Other	4 (3.7%)
	None	10 (9.3%)
	Total Valid Response	108 (100.0%)
	Total missing	2

**Table 2.11**

Question	Response	Number of Respondents (%)
What complications (or problems), to your knowledge, arise from diabetes?	Amputation	83 (76.1%)
	Foot ulcers	72 (66.1%)
	Increased risk of broken bones or fractures	33 (30.3%)
	Loss of feeling in hands or toes (neuropathy)	60 (55.0%)
	Vision loss	91 (83.5%)
	Irritable bowel disease	24 (22.0%)
	Kidney disease	88 (80.7%)
	Cardiovascular disease/Stroke	70 (64.2%)
	Other	2 (1.8%)
	Don't know/Not sure	4 (3.7%)
	None	3 (2.8%)
	Total Valid Response	109 (100.0%)
	Total missing	1

**Table 2.12**

Question	Response	Number of Respondents (%)
Which complication of diabetes are you most concerned about?	Amputation	29 (26.6)
	Foot ulcers	3 (2.8)
	Vision loss	27 (24.8)
	Kidney disease	20 (18.3)
	Cardiovascular disease/Stroke	11 (10.1)
	Other	3 (2.8)
	Don't know/Not sure	11 (10.1)
	None	5 (4.6)
	Total Valid Response	109 (100.0)
	Total missing	1

**Table 2.13**

Question	Response	Number of Respondents (%)
Which of the following complications of diabetes do you have?	Amputation	6 (5.6%)
	Foot ulcers	5 (4.6%)
	Broken bones or fractures	2 (1.9%)
	Loss of feeling in hands or toes (neuropathy)	16 (14.8%)
	Vision loss	32 (29.6%)
	Kidney disease	12 (11.1%)
	Cardiovascular disease/Stroke	7 (6.5%)
	Other	2 (1.9%)
	Don't know/Not sure	3 (2.8%)
	None	47 (43.5%)
	Total Valid Response	108 (100.0%)
	Total missing	2

**Table 2.14**

Question	Response	Number of Respondents (%)
How often do you discuss the possibility of eye complications with your health care professional?	Every visit	48 (44.0%)
	Multiple times per year	15 (13.8%)
	Once per year	12 (11.0%)
	Only when symptoms arise	8 (7.3%)
	Never	21 (19.3%)
	Don't know/Not sure	5 (4.6%)
	Total Valid Response	109 (100.0%)
	Total missing	1

**Table 2.15**

Question	Response	Number of Respondents (%)
Which of the following best describes your attitude to vision issues?	I think that vision problems are a normal part of ageing	43 (40.2%)
	I do what I can to prevent vision problems (e.g. get routine screenings, visit specialists)	73 (68.2%)
	I do not make any special effort to prevent vision problems	11 (10.3%)
	Total Valid Response	107 (100.0%)
	Total missing	3

**Table 2.16**

Question	Response	Number of Respondents (%)
What type of health insurance do you have?	Public	32 (29.4)
	Public - Private	9 (8.3)
	Private	10 (9.2)
	None	58 (53.2)
	Total Valid Response	109 (100.0)
	Total missing	1

**Table 2.17**

Question	Response	Number of Respondents (%)
Most often, how do you pay for the following types of medical care and services?		
General doctor visits (e.g. primary care doctor)	Care is free	99 (93.4)
	Insurance pays total cost	3 (2.8)
	Insurance and out-of-pocket/cash (e.g. co-pays)	2 (1.9)
	Out-of-pocket only (pay cash for all care)	2 (1.9)
	Total Valid Response	106 (100.0)
	Total missing	4
Specialist medical visits (e.g. eye doctor, gynecologist, urologist)	Care is free	88 (84.6)
	Insurance pays total cost	8 (7.7)
	Insurance and out-of-pocket/cash (e.g. co-pays)	4 (3.8)
	Out-of-pocket only (pay cash for all care)	4 (3.8)
	Total Valid Response	104 (100.0)
	Total missing	6
Medicines	Care is free	96 (91.4)
	Insurance pays total cost	2 (1.9)
	Insurance and out-of-pocket/cash (e.g. co-pays)	4 (3.8)
	Out-of-pocket only (pay cash for all care)	3 (2.9)
	Total Valid Response	105 (100.0)
	Total missing	5
Medical supplies (e.g. blood glucose meter/strips)	Care is free	92 (88.5)
	Insurance pays total cost	1 (1.0)
	Insurance and out-of-pocket/cash (e.g. co-pays)	4 (3.8)
	Out-of-pocket only (pay cash for all care)	5 (4.8)
	Do not use service	2 (1.9)

Question	Response	Number of Respondents (%)
	Total Valid Response	104 (100.0)
	Total missing	6
Procedures	Care is free	92 (88.5)
	Insurance pays total cost	3 (2.9)
	Insurance and out-of-pocket/cash (e.g. co-pays)	4 (3.8)
	Out-of-pocket only (pay cash for all care)	2 (1.9)
	Do not use service	3 (2.9)
	Total Valid Response	104 (100.0)
	Total missing	6
Tests/screenings	Care is free	98 (93.3)
	Insurance pays total cost	2 (1.9)
	Insurance and out-of-pocket/cash (e.g. co-pays)	2 (1.9)
	Out-of-pocket only (pay cash for all care)	2 (1.9)
	Don't know/Not Sure	1 (1.0)
	Total Valid Response	105 (100.0)
	Total missing	5
Health education	Care is free	37 (72.5)
	Out-of-pocket only (pay cash for all care)	1 (2.0)
	Do not use service	8 (15.7)
	Don't know/Not Sure	5 (9.8)
	Total Valid Response	51 (100.0)
	Total missing	59
Counseling	Care is free	36 (72.0)
	Out-of-pocket only (pay cash for all care)	1 (2.0)
	Do not use service	7 (14.0)
	Don't know/Not Sure	6 (12.0)
	Total Valid Response	50 (100.0)
	Total missing	60

**Table 3.1**

Question	Response	Number of Respondents (%)
Are you aware of any government sponsored screening programs for diabetic eye disease (diabetic retinopathy)?	Yes	40 (37.4%)
	No	67 (62.6%)
	Total valid response	107 (100.0%)
	Total missing	3

**Table 3.2**

Question	Response	Number of Respondents (%)
Have you ever had an eye exam for diabetic eye disease?	Yes	95 (88.0%)
	No	13 (12.0%)
	Total valid response	108 (100.0%)
	Total missing	2
How long ago was your last eye exam?	Within the last year	80 (84.2%)
	More than 1 year ago but less than 2 years	9 (9.5%)
	More than 2 years ago but less than 3 years	1 (1.1%)
	More than 3 years ago but less than 5 years	2 (2.1%)
	Five or more years ago	2 (2.1%)
	Don't know/Not sure	1 (1.1%)
	Total valid response	95 (100.0%)
	Total missing	15
Who did the last exam?	General/Family practitioner	20 (21.3%)
	Eye doctor/Eye clinic	63 (67.0%)
	Other	8 (8.5%)
	Don't know/Not sure	3 (3.2%)
	Total valid response	94 (100.0%)
	Total missing	16

**Table 3.3**



Question	Response	Number of Respondents (%)
Have you ever had a dilated eye exam, where your eyes are examined after eye drops?	Yes	76 (71.7%)
	No	16 (15.1%)
	Don't know/Not sure	14 (13.2%)
	Total valid response	106 (100.0%)
	Total missing	4

**Table 3.4**

Question	Response	Number of Respondents (%)
Based on what you know, how often should you get your eyes examined for diabetic eye disease?	Once a year	85 (78.7%)
	Every two years	6 (5.6%)
	Never	2 (1.9%)
	Don't know/Not sure	15 (13.9%)
	Total valid response	108 (100.0%)
	Total missing	2

**Table 3.5**

Question	Response	Number of Respondents (%)
For you, what are the biggest barriers to eye exams?	They are expensive	9 (8.4%)
	Eye exams are not available near my home	9 (8.4%)
	Long wait time for appointment	33 (30.8%)
	Long wait time on the day of the visit	42 (39.3%)
	Referral process is complicated or takes too long	8 (7.5%)
	Recommended treatments for eye problems are not available	6 (5.6%)
	Don't know much about my condition	8 (7.5%)
	Fear of treatment/results	5 (4.7%)

Question	Response	Number of Respondents (%)
	Burden on my family/friends	9 (8.4%)
	Limited access to diabetes specialists	5 (4.7%)
	I'm not likely to have eye complications	3 (2.8%)
	Eye exams are not important	1 (0.9%)
	Too many other things to do or worry about	4 (3.7%)
	Clinics are too small or lack necessary equipment/staff	2 (1.9%)
	Other	34 (31.8%)
	Total valid response	107 (100.0%)
	Total missing	3

**Table 3.6**

Question	Response	Number of Respondents (%)
Have you been diagnosed with diabetic eye disease?	Yes	39 (36.1%)
	No	69 (63.9%)
	Total valid response	108 (100.0%)
	Total missing	2
Has your diabetic eye disease affected your vision?	Yes, slightly	17 (43.6%)
	Yes, significantly	14 (35.9%)
	No	8 (20.5%)
	Total valid response	39 (100.0%)
	Total missing	71
Have vision issues caused you to have difficulty with any of the following?	Traveling	15 (50.0%)
	Household responsibilities, such as cooking or cleaning	8 (26.7%)
	Social interactions with family/friends	8 (26.7%)
	Leisure activities/exercise	6 (20.0%)
	Work or keeping a job	5 (16.7%)
	Managing my diabetes	4 (13.3%)

Question	Response	Number of Respondents (%)
	Other	1 (3.3%)
	None	8 (26.7%)
	Driving (a car/vehicle)	9 (30.0%)
	Total valid response	30 (100.0%)
	Total missing	80

**Table 3.7**

Question	Response	Number of Respondents (%)
Have you had any treatment for diabetic eye disease?	Yes	28 (71.8%)
	No	10 (25.6%)
	Don't know/Not sure	1 (2.6%)
	Total valid response	39 (100.0%)
	Total missing	71
What treatment did you receive?	Laser	24 (88.9%)
	Injection in the eye (Anti-VEGF)	5 (18.5%)
	Surgery	1 (3.7%)
	Other	2 (7.4%)
	Total valid response	27 (100.0%)
	Total missing	83
Did you complete the treatment?	Yes	22 (81.5%)
	Still receiving treatment	4 (14.8%)
	Don't know/Not sure	1 (3.7%)
	Total valid response	27 (100.0%)
	Total missing	83
Do you feel that the treatment worked?	Yes, and vision improved	16 (59.3%)
	Yes, but vision stayed the same	6 (22.2%)
	No	2 (7.4%)
	Still waiting to know	2 (7.4%)
	Don't know/Not sure	1 (3.7%)
	Total valid response	27 (100.0%)

Question	Response	Number of Respondents (%)
	Total missing	83
What is/are the reason(s) that you did not complete the treatment?	Total missing	110
What are the reason(s) that you have not had treatment for diabetic eye disease?	My doctor did not recommend any treatment	9 (90.0%)
	Other	1 (10.0%)
	Total valid response	10 (100.0%)
	Total missing	100

**Table 3.8**

Question	Response	Number of Respondents (%)
Have you been diagnosed with diabetic macular edema?	Yes	9 (8.5%)
	No	86 (81.1%)
	Don't know/Not sure	11 (10.4%)
	Total valid response	106 (100.0%)
	Total missing	4
If Yes, which of the following would you prefer	Treatment to prevent further vision loss	8 (88.9%)
	Only treatment when vision loss has occurred	1 (11.1%)
	Total valid response	9 (100.0%)
	Total missing	101

**Table 3.9**

Question	Response	Number of Respondents (%)
Have you received information about diabetic retinopathy or diabetic macular edema from any of the following sources?	Doctor/Nurse	71 (67.0%)
	Health educator	11 (10.4%)
	Diabetes organization or other health organization	7 (6.6%)
	Family/Friends/Neighbors	14 (13.2%)

Question	Response	Number of Respondents (%)
	TV/Radio/Newspaper/Magazines	19 (17.9%)
	Internet	7 (6.6%)
	None of the above	26 (24.5%)
	Total valid response	106 (100.0%)
	Total missing	4

**Table 4.1**

Question	Response	Number of Respondents (%)
What is your gender?	Female	72 (67.9)
	Male	34 (32.1)
	Total Valid Response	106 (100.0)
	Total missing	4
Please indicate your age	18 - 29	2 (1.8)
	30 - 39	4 (3.6)
	40 - 49	12 (10.9)
	50 - 59	35 (31.8)
	60 - 69	37 (33.6)
	70 - 79	20 (18.2)
	Total Valid Response	110 (100.0)

**Table 4.2**

Question	Response	Number of Respondents (%)
Where do you live?	Urban setting	100 (93.5)
	Non-urban setting	7 (6.5)
	Total Valid Response	107 (100.0)
	Total missing	3

**Table 4.3**

Question	Response	Number of Respondents (%)
What is the highest level of education you completed?	Did not complete primary school	10 (9.3)
	Primary school	28 (26.2)

Question	Response	Number of Respondents (%)
	Secondary school	44 (41.1)
	College/University	17 (15.9)
	Graduate or post-graduate	8 (7.5)
	Total valid response	107 (100.0)
	Total missing	3

**Table 4.4**

Question	Response	Number of Respondents (%)
Are you currently working?	Working for pay	28 (26.2)
	Working without pay at home (e.g. housework, farming)	8 (7.5)
	Retired	30 (28.0)
	Not working	41 (38.3)
	Total Valid Response	107 (100.0)
	Total missing	3

**Table 4.5**

Question	Response	Number of Respondents (%)
Do you receive assistance from the government?	Income assistance	13 (12.6%)
	Medical assistance	27 (26.2%)
	Housing assistance	1 (1.0%)
	Pension assistance	20 (19.4%)
	None of the above	49 (47.6%)
	Total valid response	103 (100.0%)
	Total missing	7

**Table 4.6**

Question	Response	Number of Respondents (%)
Did you have trouble paying for food at anytime	Yes	9 (8.7)



Question	Response	Number of Respondents (%)
during the past year?		
	No	95 (91.3)
	Total Valid Response	104 (100.0)
	Total missing	6

**Table 4.7**

Question	Response	Number of Respondents (%)
Do you feel that your access to health care is negatively affected by any of the following?	Age	11 (10.3)
	Education	2 (1.9)
	Gender	3 (2.8)
	Income	3 (2.8)
	Language you speak	2 (1.9)
	Place where you live	9 (8.4)
	None of the above	85 (79.4)
	Total valid response	107 (100.0)
	Total missing	3

**Table 4.8**

Question	Response	Number of Respondents (%)
Which of the following do you worry about most?	Food	4 (3.8)
	Money	13 (12.3)
	Health	57 (53.8)
	Family	3 (2.8)
	None of the above	29 (27.4)
	Total Valid Response	106 (100.0)
	Total missing	4

**Table 5.1**

Question	Response	Number of Respondents (%)
In general, would you say your health is:	Excellent	1 (0.9%)
	Very good	7 (6.6%)
	Good	49 (46.2%)
	Total good health	57 (53.8%)
	Fair	42 (39.6%)
	Poor	7 (6.6%)
	Fair or poor health	49 (46.2%)
	Total valid response	106 (100.0%)
	Total missing	4

**Table 5.2**

Question	Response	Number of Respondents (%)
How many days during last 30 days was your physical health not good	Any unhealthy days	13 (14.6%)
	1-5 unhealthy days	8 (9.0%)
	6-10 unhealthy days	2 (2.2%)
	11-20 unhealthy days	3 (3.4%)
	No unhealthy days	76 (85.4%)
	Total valid response	89 (100.0%)
	Total missing	21

**Table 5.3.1**

Question	Response	Number of Respondents (%)
How many days during last 30 days was your mental health not good	Any unhealthy days	6 (6.3%)
	1-5 unhealthy days	3 (3.2%)
	6-10 unhealthy	1 (1.1%)

Question	Response	Number of Respondents (%)
	days	
	11-20 unhealthy days	2 (2.1%)
	No unhealthy days	89 (93.7%)
	Total valid response	95 (100.0%)
	Total missing	15

**Table 5.3.2**

Question	Response	Number of Respondents (%)
Unhealthy days (physically or mentally unhealthy, max 30)	Any unhealthy days	14 (16.1%)
	1-5 unhealthy days	8 (9.2%)
	6-10 unhealthy days	2 (2.3%)
	11-20 unhealthy days	2 (2.3%)
	21-30 unhealthy days	2 (2.3%)
	No unhealthy days	73 (83.9%)
	Total valid response	87 (100.0%)

**Table 5.4**

Question	Response	Number of Respondents (%)
How many days during last 30 days did poor health limit your usual activities	Any unhealthy days	7 (28.0%)
	1-5 unhealthy days	4 (16.0%)
	6-10 unhealthy days	1 (4.0%)
	11-20 unhealthy days	1 (4.0%)

Question	Response	Number of Respondents (%)
	21-30 unhealthy days	1 (4.0%)
	No unhealthy days	18 (72.0%)
	Total valid response	25 (100.0%)
	Total missing	85

**Table 5.5**

Question	Response	Number of Respondents (%)
Are you limited in any way in any activities because of any impairment or health problem?	Yes	26 (25.2%)
	No	77 (74.8%)
	Total valid response	103 (100.0%)
	Total missing	7
Which impairment or health problem, if any, limits your activities?		
a) Arthritis/rheumatism	Yes	6 (85.7%)
	No	1 (14.3%)
	Total valid response	7 (100.0%)
	Total missing	103
b) Back or neck problem	Yes	1 (25.0%)
	No	3 (75.0%)
	Total valid response	4 (100.0%)
	Total missing	106
c) Fractures, bone/joint injury	Yes	3 (60.0%)
	No	1 (20.0%)
	Don't know/Not sure	1 (20.0%)
	Total valid response	5 (100.0%)
	Total missing	105

Question	Response	Number of Respondents (%)
d) Walking problem	Yes	9 (81.8%)
	No	1 (9.1%)
	Refused	1 (9.1%)
	Total valid response	11 (100.0%)
	Total missing	99
e) Lung/breathing problem	Yes	1 (33.3%)
	No	2 (66.7%)
	Total valid response	3 (100.0%)
	Total missing	107
f) Hearing problem	Yes	3 (60.0%)
	No	2 (40.0%)
	Total valid response	5 (100.0%)
	Total missing	105
g) Eye/vision problem	Yes	12 (80.0%)
	No	2 (13.3%)
	Don't know/Not sure	1 (6.7%)
	Total valid response	15 (100.0%)
	Total missing	95
h) Heart problem	Yes	2 (40.0%)
	No	2 (40.0%)
	Don't know/Not sure	1 (20.0%)
	Total valid response	5 (100.0%)
	Total missing	105
i) Stroke problem	Yes	2 (50.0%)
	No	1 (25.0%)
	Refused	1 (25.0%)
	Total valid response	4 (100.0%)

Question	Response	Number of Respondents (%)
	Total missing	106
j) Hypertension/high blood pressure	Yes	11 (84.6%)
	No	1 (7.7%)
	Don't know/Not sure	1 (7.7%)
	Total valid response	13 (100.0%)
	Total missing	97
k) Diabetes	Yes	15 (83.3%)
	No	3 (16.7%)
	Total valid response	18 (100.0%)
	Total missing	92
l) Cancer	Yes	2 (40.0%)
	No	3 (60.0%)
	Total valid response	5 (100.0%)
	Total missing	105
m) Mental or emotional health	No	2 (100.0%)
	Total valid response	2 (100.0%)
	Total missing	108

## PT 1.2

Analysis Sets	Number of Respondents (%)
All valid respondents	50 (100.0%)
Included in Provider Analysis Set (PAS)	50 (100.0%)
Excluded in Provider Analysis Set (PAS)	0 (0.0%)
Reasons for exclusion from Provider Analysis Set:	
No other valid survey data	0
Provider Analysis Set	50
Included in the Eye Care Professional Set (Eye Specialist)	17 (34.0%)
Excluded in the Eye Care Professional Set (Eye Specialist)	33 (66.0%)



Analysis Sets	Number of Respondents (%)
Reasons for exclusion from Eye Care Professional Set:	
Missing required speciality	33
No valid (non-missing) response for the supplemental eye questionnaire	0

### PT 1.3

Subgroups	Number of Respondents (%)
Provider Analysis Set	50 (100.0%)
Primary Care Provider	8 (16.0%)
Diabetes Specialist Provider	5 (10.0%)
Eye Care Professional	17 (34.0%)
Ophthalmologist	15 (30.0%)

NB [1]: Primary Care Provider = General Practitioner/Family practitioner (but not diabetes specialist or eye care professional)

NB [2]: Diabetes specialist provider = Diabetes specialist (but not eye care professional)

NB [4]: Ophthalmologist = General ophthalmologist or retinal specialist

NB [5]: Note that providers may have selected more than one specialty

### PT 1.4

Item	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
What is your specialty?	General primary care/Family practitioner	8 (100.0%)	1 (20.0%)	0 (0.0%)	9 (18.0%)
	Diabetes specialist	0 (0.0%)	5 (100.0%)	0 (0.0%)	5 (10.0%)
	General ophthalmologist	0 (0.0%)	0 (0.0%)	7 (46.7%)	7 (14.0%)
	Optometrist	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (4.0%)
	Retinal specialist	0 (0.0%)	0 (0.0%)	9 (60.0%)	9 (18.0%)
	Nurse	0 (0.0%)	2 (40.0%)	0 (0.0%)	12 (24.0%)
	Health educator	1 (12.5%)	0 (0.0%)	0 (0.0%)	9 (18.0%)
	None of the above	0 (0.0%)	0 (0.0%)	0 (0.0%)	4 (8.0%)
	Total valid response	8 (100.0%)	5 (100.0%)	15 (100.0%)	50 (100.0%)
	Total missing	0	0	0	0

### PT 1.5

Item	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
How long have you been practicing in this profession?	Total valid response (n)	8	5	15	49
	Mean	12.5	8.4	13.2	13.4
	SD	9.0	1.7	6.8	12.7
	Median	14.5	8.0	12.0	10.0
	Min.	2	6	3	0
	Max.	30	10	30	80
	Total missing	0	0	0	1

#### PT 2.1

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
What is your main practice setting?	Diabetes clinic/practice	0 (0.0%)	2 (40.0%)	0 (0.0%)	14 (29.2%)
	Eye clinic/practice	0 (0.0%)	0 (0.0%)	7 (46.7%)	8 (16.7%)
	General medical clinic/practice	6 (85.7%)	1 (20.0%)	0 (0.0%)	8 (16.7%)
	Hospital	1 (14.3%)	2 (40.0%)	8 (53.3%)	15 (31.3%)
	Other	0 (0.0%)	0 (0.0%)	0 (0.0%)	3 (6.3%)
	Total Valid Response	7 (100.0%)	5 (100.0%)	15 (100.0%)	48 (100.0%)
	Total missing	1	0	0	2

#### PT 2.2

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Where is your main practice located?	Urban setting	4 (57.1%)	5 (100.0%)	15 (100.0%)	40 (83.3%)
	Non-urban setting	3 (42.9%)	0 (0.0%)	0 (0.0%)	8 (16.7%)
	Total Valid	7 (100.0%)	5 (100.0%)	15 (100.0%)	48

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Response				(100.0%)
	Total missing	1	0	0	2

### PT 2.3

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
In which sector is your main practice?	Government	4 (57.1%)	1 (20.0%)	5 (33.3%)	20 (41.7%)
	Private	3 (42.9%)	4 (80.0%)	8 (53.3%)	24 (50.0%)
	Non profit	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (2.1%)
	Combined/mixed	0 (0.0%)	0 (0.0%)	2 (13.3%)	3 (6.3%)
	Total Valid Response	7 (100.0%)	5 (100.0%)	15 (100.0%)	48 (100.0%)
	Total missing	1	0	0	2

### PT 2.4

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Is your main practice limited to certain populations?	No	5 (71.4%)	3 (60.0%)	14 (93.3%)	40 (85.1%)
	Yes, limited by age	1 (14.3%)	0 (0.0%)	0 (0.0%)	2 (4.3%)
	Yes, limited by gender	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (2.1%)
	Yes, limited to persons with health insurance	0 (0.0%)	0 (0.0%)	1 (6.7%)	2 (4.3%)
	Yes, limited to low income or uninsured persons	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (2.1%)
	Yes, limited to persons who pay	0 (0.0%)	2 (40.0%)	0 (0.0%)	2 (4.3%)

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	out-of-pocket				
	Yes, other	1 (14.3%)	0 (0.0%)	0 (0.0%)	2 (4.3%)
	Total valid response	7 (100.0%)	5 (100.0%)	15 (100.0%)	47 (100.0%)
	Total missing	1	0	0	3

#### PT 2.5

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
What is the average wait time for an appointment in your main practice?	Less than 1 week	3 (50.0%)	0 (0.0%)	5 (35.7%)	10 (24.4%)
	More than 1 week but less than 1 month	1 (16.7%)	1 (20.0%)	3 (21.4%)	7 (17.1%)
	More than 1 month but less than 2 months	1 (16.7%)	1 (20.0%)	4 (28.6%)	9 (22.0%)
	More than 2 months but less than 3 months	0 (0.0%)	2 (40.0%)	1 (7.1%)	6 (14.6%)
	More than 3 months but less than 6 months	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (4.9%)
	Do not take appointments	1 (16.7%)	1 (20.0%)	1 (7.1%)	4 (9.8%)
	Other	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (4.9%)
	Don't know/Not sure	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (2.4%)
	Total Valid Response	6 (100.0%)	5 (100.0%)	14 (100.0%)	41 (100.0%)
	Total missing	2	0	1	9

#### PT 2.6

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
On average, how many patients do you see per week in your main practice [n patients]	Total valid response (n)	6	4	14	38
	Mean	115	159.3	82.1	92.5
	SD	88.9	230.6	57	115.5
	Median	100	65	70	50
	Min.	20	7	20	4
	Max.	240	500	200	500
	Total missing	2	1	1	12
What percentage of the patients in your main practice have diabetes [% patients]	Total valid response (n)	6	4	14	37
	Mean	30	52.5	40.2	47.5
	SD	15.5	25	13.4	27.9
	Median	30	55	40	40
	Min.	10	20	20	10
	Max.	50	80	70	100
	Total missing	2	1	1	13

#### PT 2.7

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
In your main practice, how do patients pay for the care and services that you provide?	Don't pay	1 (16.7%)	1 (20.0%)	3 (21.4%)	9 (22.0%)
	Pay a reduced/subsidized rate	3 (50.0%)	0 (0.0%)	7 (50.0%)	15 (36.6%)
	Pay out-of-pocket (full fees)	2 (33.3%)	4 (80.0%)	4 (28.6%)	15 (36.6%)

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Pay through insurance	0 (0.0%)	2 (40.0%)	4 (28.6%)	11 (26.8%)
	Patient pays some, insurance pays some	2 (33.3%)	1 (20.0%)	4 (28.6%)	10 (24.4%)
	Other	1 (16.7%)	1 (20.0%)	0 (0.0%)	5 (12.2%)
	Total valid response	6 (100.0%)	5 (100.0%)	14 (100.0%)	41 (100.0%)
	Total missing	2	0	1	9

**PT 2.8**

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
In addition to your main practice, do you work in another practice setting?	Yes	3 (50.0%)	5 (100.0%)	5 (35.7%)	18 (43.9%)
	No	3 (50.0%)		9 (64.3%)	23 (56.1%)
	Total valid response	6 (100.0%)	5 (100.0%)	14 (100.0%)	41 (100.0%)
	Total missing	2		1	9
In which other practice setting(s) do you work?	Hospital		3 (60.0%)	4 (80.0%)	7 (41.2%)
	General medical clinic/practice	2 (66.7%)	2 (40.0%)		4 (23.5%)
	Diabetes clinic/practice		2 (40.0%)		3 (17.6%)
	Eye clinic/practice			2 (40.0%)	3 (17.6%)
	Other	1 (33.3%)			3 (17.6%)
	Total valid response	3 (100.0%)	5 (100.0%)	5 (100.0%)	17 (100.0%)
	Total missing	5		10	33
In which sector(s)	Government	2 (66.7%)	1 (20.0%)	2 (40.0%)	7

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
is(are) the practice(s)?					(41.2%)
	Private	1 (33.3%)	4 (80.0%)	3 (60.0%)	9 (52.9%)
	Non profit				1 (5.9%)
	Total valid response	3 (100.0%)	5 (100.0%)	5 (100.0%)	17 (100.0%)
	Total missing	5		10	33
Is there a major difference between your practices with respect to how diabetic eye disease is screened and managed?	Yes	1 (33.3%)	3 (75.0%)	2 (40.0%)	9 (56.3%)
	No	2 (66.7%)	1 (25.0%)	3 (60.0%)	7 (43.8%)
	Total valid response	3 (100.0%)	4 (100.0%)	5 (100.0%)	16 (100.0%)
	Total missing	5	1	10	34

#### PT 2.9

Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Blood glucose	Yes		6 (100.0%)	5 (100.0%)	13 (92.9%)	37 (97.4%)
		Total valid numeric response (n)	6 (100.0%)	4 (80.0%)	11 (78.6%)	34 (89.5%)
		Mean	11.8	6.5	21.1	38.9
		SD	10.0	4.1	59.4	97.6
		Median	9.0	6.0	3.0	4.0
		Min	4	2	1	0
		Max	30	12	200	365
		Total missing	2	1	4	16
	No				1 (7.1%)	1 (2.6%)
	Total valid		6	5 (100.0%)	14 (100.0%)	38

Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS		
	response		(100.0%)			(100.0%)		
	Total missing		2		1	12		
HbA1c	Yes		6 (100.0%)	5 (100.0%)	10 (76.9%)	32 (86.5%)		
		Total valid numeric response (n)	6 (100.0%)	4 (80.0%)	8 (61.5%)	29 (78.4%)		
		Mean	3.8	3.5	2.4	3.0		
		SD	4.2	1.0	0.5	2.0		
		Median	2.5	4.0	2.0	2.0		
		Min	1	2	2	1		
		Max	12	4	3	12		
		Total missing	2	1	7	21		
	No				3 (23.1%)	5 (13.5%)		
	Total valid response				6 (100.0%)	5 (100.0%)	13 (100.0%)	37 (100.0%)
	Total missing				2		2	13
Urine check	Yes		6 (100.0%)	5 (100.0%)	6 (54.5%)	27 (79.4%)		
			Total valid numeric response (n)	6 (100.0%)	4 (80.0%)	5 (45.5%)	25 (73.5%)	
			Mean	7.8	4.5	3.6	4.0	
			SD	11.0	1.9	1.1	5.7	
			Median	3.5	5.0	4.0	3.0	
			Min	2	2	2	0	
			Max	30	6	5	30	
		Total missing	2	1	10	25		
	No				5 (45.5%)	7 (20.6%)		
	Total				6	5 (100.0%)	11 (100.0%)	34



Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	valid response		(100.0%)			(100.0%)
	Total missing		2		4	16
Weight check	Yes		6 (100.0%)	5 (100.0%)	8 (66.7%)	30 (83.3%)
		Total valid numeric response (n)	6 (100.0%)	4 (80.0%)	7 (58.3%)	28 (77.8%)
		Mean	5.8	6.8	3.4	17.2
		SD	3.3	3.8	1.3	68.2
		Median	5.0	6.0	4.0	4.0
		Min	3	3	1	0
		Max	12	12	5	365
		Total missing	2	1	8	22
	No				4 (33.3%)	6 (16.7%)
	Total valid response		6 (100.0%)	5 (100.0%)	12 (100.0%)	36 (100.0%)
	Total missing		2		3	14
Blood pressure check	Yes		6 (100.0%)	5 (100.0%)	11 (84.6%)	34 (89.5%)
		Total valid numeric response (n)	6 (100.0%)	4 (80.0%)	10 (76.9%)	32 (84.2%)
		Mean	11.5	6.8	22.0	22.7
		SD	5.9	3.8	62.6	71.5
		Median	12.0	6.0	3.0	4.0
		Min	4	3	0	0
		Max	20	12	200	365
		Total missing	2	1	5	18
	No				2 (15.4%)	4 (10.5%)

Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS	
	Total valid response		6 (100.0%)	5 (100.0%)	13 (100.0%)	38 (100.0%)	
	Total missing		2		2	12	
Foot check	Yes		6 (100.0%)	4 (100.0%)	3 (27.3%)	27 (77.1%)	
		Total valid numeric response (n)	6 (100.0%)	3 (75.0%)	2 (18.2%)	25 (71.4%)	
		Mean	5.7	1.0	1.5	6.6	
		SD	6.2	0.0	2.1	15.0	
		Median	2.5	1.0	1.5	1.0	
		Min	1	1	0	0	
		Max	15	1	3	60	
		Total missing	2	2	13	25	
No					8 (72.7%)	8 (22.9%)	
Total valid response	6 (100.0%)				4 (100.0%)	11 (100.0%)	35 (100.0%)
Total missing	2				1	4	15
Eye examination - Un-dilated	Yes		6 (100.0%)	4 (80.0%)	8 (61.5%)	28 (73.7%)	
		Total valid numeric response (n)	6 (100.0%)	4 (80.0%)	7 (53.8%)	27 (71.1%)	
		Mean	3.0	1.0	54.3	15.3	
		SD	4.4	0.0	137.0	69.9	
		Median	1.0	1.0	3.0	1.0	
		Min	1	1	1	0	
		Max	12	1	365	365	
		Total missing	2	1	8	23	

Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	No			1 (20.0%)	5 (38.5%)	10 (26.3%)
	Total valid response		6 (100.0%)	5 (100.0%)	13 (100.0%)	38 (100.0%)
	Total missing		2		2	12
Eye examination - Optical Coherence Tomography	Yes				13 (92.9%)	17 (48.6%)
		Total valid numeric response (n)	0 (0.0%)	0 (0.0%)	11 (78.6%)	15 (42.9%)
		Mean			11.0	8.3
		SD			29.6	25.4
		Median			2.0	1.0
		Min			0	0
		Max			100	100
		Total missing	8	5	4	35
	No		6 (100.0%)	4 (100.0%)	1 (7.1%)	18 (51.4%)
	Total valid response		6 (100.0%)	4 (100.0%)	14 (100.0%)	35 (100.0%)
	Total missing		2	1	1	15
Eye examination - Fundoscopy	Yes		4 (66.7%)	5 (100.0%)	14 (100.0%)	32 (84.2%)
		Total valid numeric response (n)	4 (66.7%)	4 (80.0%)	12 (85.7%)	29 (76.3%)
		Mean	3.8	1.0	33.0	14.6
		SD	5.5	0.0	104.6	67.4
		Median	1.0	1.0	3.0	1.0

Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
		Min	1	1	1	0
		Max	12	1	365	365
		Total missing	4	1	3	21
	No		2 (33.3%)			6 (15.8%)
	Total valid response		6 (100.0%)	5 (100.0%)	14 (100.0%)	38 (100.0%)
	Total missing		2		1	12
Eye examination - Fluorescein Angiography	Yes			1 (25.0%)	11 (78.6%)	15 (44.1%)
		Total valid numeric response (n)	0 (0.0%)	1 (25.0%)	9 (64.3%)	13 (38.2%)
		Mean		0.0	11.7	8.2
		SD			33.1	27.6
		Median		0.0	1.0	1.0
		Min		0	0	0
		Max		0	100	100
		Total missing	8	4	6	37
	No		6 (100.0%)	3 (75.0%)	3 (21.4%)	19 (55.9%)
	Total valid response		6 (100.0%)	4 (100.0%)	14 (100.0%)	34 (100.0%)
	Total missing		2	1	1	16
Eye examination - Lipid check	Yes		4 (66.7%)	1 (25.0%)	7 (63.6%)	18 (56.3%)
		Total valid numeric response (n)	4 (66.7%)	1 (25.0%)	6 (54.5%)	17 (53.1%)

Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
		Mean	1.8	0.0	1.8	1.7
		SD	0.5		1.5	1.4
		Median	2.0	0.0	1.5	2.0
		Min	1	0	0	0
		Max	2	0	4	4
		Total missing	4	4	9	33
	No		2 (33.3%)	3 (75.0%)	4 (36.4%)	14 (43.8%)
	Total valid response		6 (100.0%)	4 (100.0%)	11 (100.0%)	32 (100.0%)
	Total missing		2	1	4	18

#### PT 2.10

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
In your main practice, what topics do you cover during a routine visit with a patient who has diabetes?	Diabetes management and monitoring	6 (100.0%)	4 (100.0%)	8 (66.7%)	30 (85.7%)
	Diet/nutrition	5 (83.3%)	3 (75.0%)	4 (33.3%)	25 (71.4%)
	Exercise/physical activity	5 (83.3%)	3 (75.0%)	4 (33.3%)	23 (65.7%)
	Medicines	5 (83.3%)	4 (100.0%)	3 (25.0%)	22 (62.9%)
	Foot care and inspection	4 (66.7%)	2 (50.0%)	0 (0.0%)	16 (45.7%)
	Blood pressure	5 (83.3%)	4 (100.0%)	5 (41.7%)	23 (65.7%)
	Eye care and exams	3 (50.0%)	2 (50.0%)	11 (91.7%)	22 (62.9%)
	Lipid check	4 (66.7%)	4 (100.0%)	1 (8.3%)	14

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
					(40.0%)
	Total valid response	6 (100.0%)	4 (100.0%)	12 (100.0%)	35 (100.0%)
	Total missing	2	1	3	15

#### PT 2.11

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Is there written information about diabetes available for patients in your main practice?	Yes, and information on eye complications is sufficient	0 (0.0%)	0 (0.0%)	5 (41.7%)	11 (31.4%)
	Yes, but information on eye complications is not sufficient	5 (83.3%)	3 (75.0%)	3 (25.0%)	17 (48.6%)
	No written information is available for patients	1 (16.7%)	1 (25.0%)	4 (33.3%)	7 (20.0%)
	Total Valid Response	6 (100.0%)	4 (100.0%)	12 (100.0%)	35 (100.0%)
	Total missing	2	1	3	15

#### PT 2.12

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Do you have written protocols/guidelines available in your main practice for the management of diabetes?	Yes, available and used by staff	5 (83.3%)	2 (50.0%)	5 (41.7%)	22 (62.9%)
	Yes, available but not used by staff	0 (0.0%)	2 (50.0%)	1 (8.3%)	3 (8.6%)

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Not available	1 (16.7%)	0 (0.0%)	6 (50.0%)	9 (25.7%)
	Don't know/Not sure	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (2.9%)
	Total Valid Response	6 (100.0%)	4 (100.0%)	12 (100.0%)	35 (100.0%)
	Total missing	2	1	3	15

#### PT 2.13

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Do you have written protocols/guidelines for detection and management of diabetes-related vision issue available in your main practice?	Yes, available and used by staff	4 (66.7%)	0 (0.0%)	4 (33.3%)	15 (44.1%)
	Yes, available but not used by staff	0 (0.0%)	1 (33.3%)	2 (16.7%)	4 (11.8%)
	Not available	2 (33.3%)	1 (33.3%)	5 (41.7%)	12 (35.3%)
	Don't know/Not sure	0 (0.0%)	1 (33.3%)	1 (8.3%)	3 (8.8%)
	Total Valid Response	6 (100.0%)	3 (100.0%)	12 (100.0%)	34 (100.0%)
	Total missing	2	2	3	16

#### PT 2.14

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
What is the	After a	3 (50.0%)	1 (25.0%)	4 (33.3%)	10

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
protocol in your main practice for timing of initial eye exams for persons with diabetes - Type I?	predetermined number of years (numeric response) (n)				(28.6%)
	Mean	4.0	5.0	4.5	4.1
	SD	1.7		1.0	1.5
	Median	5.0	5.0	5.0	5.0
	Min	2	5	3	1
	Max	5	5	5	5
	After a predetermined age (numeric response) (n)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	Mean				
	SD				
	Median				
	Min				
	Max				
	As soon as they are diagnosed	2 (33.3%)		6 (50.0%)	11 (31.4%)
	When a patient reports eye/vision problems				1 (2.9%)
	No standard practice, timing varies case by case	1 (16.7%)	3 (75.0%)	2 (16.7%)	10 (28.6%)
	Don't know/Not sure				3 (8.6%)
	Total valid response	6 (100.0%)	4 (100.0%)	12 (100.0%)	35 (100.0%)
	Total missing	2	1	3	15
What is the protocol in your main practice for timing of initial eye exams for persons with diabetes -	After a predetermined number of years (numeric response) (n)	1 (16.7%)	0 (0.0%)	0 (0.0%)	1 (2.9%)



Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Type II?					
	Mean	2.0			2.0
	SD				
	Median	2.0			2.0
	Min	2			2
	Max	2			2
	After a predetermined age (numeric response) (n)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	Mean				
	SD				
	Median				
	Min				
	Max				
	As soon as they are diagnosed	4 (66.7%)	3 (75.0%)	11 (91.7%)	23 (65.7%)
	When a patient reports eye/vision problems	1 (16.7%)			3 (8.6%)
	No standard practice, timing varies case by case			1 (8.3%)	6 (17.1%)
	Don't know/Not sure			1 (25.0%)	2 (5.7%)
	Total valid response	6 (100.0%)	4 (100.0%)	12 (100.0%)	35 (100.0%)
	Total missing	2	1	3	15

#### PT 2.15

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
What is the protocol in your main practice for timing of follow-up eye examinations for persons	Once a year	5 (83.3%)	4 (100.0%)	10 (83.3%)	27 (77.1%)

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
with diabetes?					
	Every two years	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (2.9%)
	Other	1 (16.7%)	0 (0.0%)	2 (16.7%)	5 (14.3%)
	Don't know/Not sure	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (5.7%)
	Total Valid Response	6 (100.0%)	4 (100.0%)	12 (100.0%)	35 (100.0%)
	Total missing	2	1	3	15

**PT 2.16**

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Do you screen patients for DR?	Yes	4 (66.7%)	4 (100.0%)	12 (100.0%)	31 (88.6%)
	No	2 (33.3%)			4 (11.4%)
	Total valid response	6 (100.0%)	4 (100.0%)	12 (100.0%)	35 (100.0%)
	Total missing	2	1	3	15
Where do you screen patients?	In clinic	4 (100.0%)	4 (100.0%)	12 (100.0%)	30 (100.0%)
	Outreach			4 (33.3%)	4 (13.3%)
	Other			1 (8.3%)	1 (3.3%)
	Total valid response	4 (100.0%)	4 (100.0%)	12 (100.0%)	30 (100.0%)
	Total missing	4	1	3	20

**PT 2.17**

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
What patient characteristics influence your	Diabetes duration	4 (80.0%)	4 (100.0%)	11 (91.7%)	30 (93.8%)

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
vision care and/or vision referrals?					
	Patient's age	3 (60.0%)	3 (75.0%)	7 (58.3%)	24 (75.0%)
	Patient's gender	0 (0.0%)	0 (0.0%)	0 (0.0%)	3 (9.4%)
	Presence of comorbidities such as hypertension, etc.	4 (80.0%)	3 (75.0%)	10 (83.3%)	24 (75.0%)
	High glucose levels	4 (80.0%)	3 (75.0%)	11 (91.7%)	28 (87.5%)
	Ability or inability to pay	1 (20.0%)	3 (75.0%)	0 (0.0%)	6 (18.8%)
	Insurance restrictions	1 (20.0%)	1 (25.0%)	0 (0.0%)	2 (6.3%)
	Patient educational level	2 (40.0%)	0 (0.0%)	4 (33.3%)	9 (28.1%)
	Patient adherence to recommendations	2 (40.0%)	1 (25.0%)	3 (25.0%)	11 (34.4%)
	None of the above	1 (20.0%)	0 (0.0%)	0 (0.0%)	1 (3.1%)
	Not applicable	0 (0.0%)	0 (0.0%)	1 (8.3%)	1 (3.1%)
	Total valid response	5 (100.0%)	4 (100.0%)	12 (100.0%)	32 (100.0%)
	Total missing	3	1	3	18

#### PT 2.18

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
What are the major barriers to optimizing eye health faced by patients with diabetes in your main practice?	Cost of care	3 (60.0%)	4 (100.0%)	6 (50.0%)	18 (56.3%)
	Proximity to care	2 (40.0%)	1 (25.0%)	6 (50.0%)	13 (40.6%)
	Long wait time for appointment	2 (40.0%)	1 (25.0%)	2 (16.7%)	11 (34.4%)

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Long wait time on the day of visit	2 (40.0%)	2 (50.0%)	2 (16.7%)	13 (40.6%)
	Referral process	2 (40.0%)	1 (25.0%)	5 (41.7%)	11 (34.4%)
	Recommended treatments are not available	1 (20.0%)	0 (0.0%)	3 (25.0%)	7 (21.9%)
	Lack of knowledge and/or awareness	3 (60.0%)	2 (50.0%)	11 (91.7%)	23 (71.9%)
	Patients fear of treatment/results	3 (60.0%)	3 (75.0%)	8 (66.7%)	19 (59.4%)
	Patients they are a burden on family/friends	2 (40.0%)	1 (25.0%)	3 (25.0%)	6 (18.8%)
	Limited access to diabetes specialists	2 (40.0%)	0 (0.0%)	2 (16.7%)	6 (18.8%)
	Limited access to eye specialists	1 (20.0%)	1 (25.0%)	4 (33.3%)	10 (31.3%)
	Patients feel eye complications are unlikely	2 (40.0%)	4 (100.0%)	8 (66.7%)	17 (53.1%)
	Patients feel eye exams are not important	3 (60.0%)	3 (75.0%)	12 (100.0%)	22 (68.8%)
	Patients have competing responsibilities and priorities	4 (80.0%)	3 (75.0%)	6 (50.0%)	16 (50.0%)
	Clinic too small or lack necessary equipment/staff	2 (40.0%)	1 (25.0%)	0 (0.0%)	5 (15.6%)
	Other	1 (20.0%)	0 (0.0%)	0 (0.0%)	1 (3.1%)
	Total valid response	5 (100.0%)	4 (100.0%)	12 (100.0%)	32 (100.0%)
	Total missing	3	1	3	18

PT 2.19

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
In your main practice, are patients contacted with reminders for general follow-up appointments?	Yes	2 (40.0%)	2 (50.0%)	6 (50.0%)	15 (46.9%)
	No	3 (60.0%)	2 (50.0%)	5 (41.7%)	15 (46.9%)
	Don't know/Not sure	0 (0.0%)	0 (0.0%)	1 (8.3%)	2 (6.3%)
	Total Valid Response	5 (100.0%)	4 (100.0%)	12 (100.0%)	32 (100.0%)
	Total missing	3	1	3	18

#### PT 2.20

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Do you share relevant patient information with other health care professionals involved in the patients care e.g. his or her general practitioner, ophthalmologist, podiatrist?	Yes	4 (80.0%)	4 (100.0%)	9 (75.0%)	25 (78.1%)
	No	1 (20.0%)	0 (0.0%)	3 (25.0%)	6 (18.8%)
	Don't know/Not sure	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (3.1%)
	Total Valid Response	5 (100.0%)	4 (100.0%)	12 (100.0%)	32 (100.0%)
	Total missing	3	1	3	18

#### PT 3.1

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Please indicate your age:	18 - 29	1 (20.0%)			2 (6.3%)

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	30 - 39	1 (20.0%)	2 (50.0%)	2 (16.7%)	9 (28.1%)
	40 - 49	2 (40.0%)	2 (50.0%)	9 (75.0%)	18 (56.3%)
	50 - 59			1 (8.3%)	1 (3.1%)
	60 - 69	1 (20.0%)			2 (6.3%)
	Total valid response	5 (100.0%)	4 (100.0%)	12 (100.0%)	32 (100.0%)
	Total missing	3	1	3	18
What is your gender?	Female	3 (60.0%)	2 (50.0%)	7 (58.3%)	20 (62.5%)
	Male	2 (40.0%)	2 (50.0%)	5 (41.7%)	12 (37.5%)
	Total valid response	5 (100.0%)	4 (100.0%)	12 (100.0%)	32 (100.0%)
	Total missing	3	1	3	18
What is your highest level of education completed?	College/University		1 (25.0%)		6 (18.8%)
	Graduate or advanced degree (e.g. PhD, MD, etc)	5 (100.0%)	3 (75.0%)	12 (100.0%)	26 (81.3%)
	Total valid response	5 (100.0%)	4 (100.0%)	12 (100.0%)	32 (100.0%)
	Total missing	3	1	3	18

#### PT 4.1

Question	Response	Ophthalmologist
What percentage of your patients have diabetic retinopathy	Total valid numeric response (n)	12
	Mean	42.1
	SD	25.4
	Median	40.0
	Min	10
	Max	90

Question	Response	Ophthalmologist
	Total missing	3

#### PT 4.2

Question	Response	Ophthalmologist
What percentage of your patients have diabetic macular edema?	Total valid numeric response (n)	12
	Mean	25.9
	SD	18.6
	Median	25.0
	Min	3
	Max	50
	Total missing	3

#### PT 4.3

Question	Response	Ophthalmologist
What is the average amount of time your patients wait for an appointment to be screened for diabetic eye disease in your practice?	Less than 1 week	5 (41.7%)
	More than 1 week but less than 1 month	2 (16.7%)
	More than 1 month but less than 2 months	2 (16.7%)
	More than 2 months but less than 3 months	2 (16.7%)
	Do not take appointment	1 (8.3%)
	Total Valid Response	12 (100.0%)
	Total missing	3

#### PT 4.4

Question	Response	Ophthalmologist
From the time a patient is screened, what is the average length of time he/she waits for diagnosis?	There is not wait, diagnosis is given when screened	12 (100.0%)
	Total Valid Response	12 (100.0%)
	Total missing	3

**PT 4.5**

Type of Treatment	Question	Response/time	Ophthalmologist
Laser photocoagulation	Is the treatment available?	Available within country	3 (25.0%)
		Available locally	3 (25.0%)
		Available in practice	12 (100.0%)
		Total valid response	12 (100.0%)
		Total missing	3
	What is the average amount of time your patients wait for a consultation appointment? (weeks)	Total valid numeric response (n)	11 (91.7%)
		Mean	1.2
		SD	0.6
		Median	1.0
		Min	0
		Max	2
		Not applicable	1 (8.3%)
		Total valid response	12 (100.0%)
		Total missing	3
	What is the average amount of time your patients wait for a first treatment?(weeks)	Total valid numeric response (n)	10 (90.9%)
		Mean	0.8
		SD	0.4
		Median	1.0
		Min	0
		Max	1
		Not applicable	1 (9.1%)
		Total valid response	11 (100.0%)
		Total missing	4
	What is the average amount of time your patients wait for a second treatment?(weeks)	Total valid numeric response (n)	10 (90.9%)
		Mean	1.6



Type of Treatment	Question	Response/time	Ophthalmologist
		SD	0.7
		Median	1.5
		Min	1
		Max	3
		Not applicable	1 (9.1%)
		Total valid response	11 (100.0%)
		Total missing	4
Anti-VEGF therapies	Is the treatment available?	Available within country	3 (25.0%)
		Available locally	3 (25.0%)
		Available in practice	12 (100.0%)
		Total valid response	12 (100.0%)
		Total missing	3
	What is the average amount of time your patients wait for a consultation appointment? (weeks)	Total valid numeric response (n)	10 (83.3%)
		Mean	1.1
		SD	0.6
		Median	1.0
		Min	0
		Max	2
		Don't know/not sure	1 (8.3%)
		Not applicable	1 (8.3%)
		Total valid response	12 (100.0%)
		Total missing	3
	What is the average amount of time your patients wait for a first treatment?(weeks)	Total valid numeric response (n)	10 (83.3%)
		Mean	0.9
		SD	0.6
		Median	1.0
		Min	0

Type of Treatment	Question	Response/time	Ophthalmologist
		Max	2
		Don't know/not sure	1 (8.3%)
		Not applicable	1 (8.3%)
		Total valid response	12 (100.0%)
		Total missing	3
	What is the average amount of time your patients wait for a second treatment?(weeks)	Total valid numeric response (n)	9 (81.8%)
		Mean	3.2
		SD	1.6
		Median	4.0
		Min	1
		Max	6
		Don't know/not sure	1 (9.1%)
		Not applicable	1 (9.1%)
		Total valid response	11 (100.0%)
		Total missing	4
Intravitreal steroid	Is the treatment available?	Available within country	3 (25.0%)
		Available locally	3 (25.0%)
		Available in practice	11 (91.7%)
		Not available	1 (8.3%)
		Total valid response	12 (100.0%)
		Total missing	3
	What is the average amount of time your patients wait for a consultation appointment? (weeks)	Total valid numeric response (n)	10 (90.9%)
		Mean	1.1
		SD	0.6
		Median	1.0
		Min	0

Type of Treatment	Question	Response/time	Ophthalmologist
		Max	2
		Not applicable	1 (9.1%)
		Total valid response	11 (100.0%)
		Total missing	4
	What is the average amount of time your patients wait for a first treatment?(weeks)	Total valid numeric response (n)	10 (90.9%)
		Mean	0.9
		SD	0.6
		Median	1.0
		Min	0
		Max	2
		Not applicable	1 (9.1%)
		Total valid response	11 (100.0%)
		Total missing	4
	What is the average amount of time your patients wait for a second treatment?(weeks)	Total valid numeric response (n)	7 (77.8%)
		Mean	3.9
		SD	3.8
		Median	3.0
		Min	1
		Max	12
		Not applicable	2 (22.2%)
		Total valid response	9 (100.0%)
		Total missing	6
Uncomplicated vitrectomy	Is the treatment available?	Available within country	3 (25.0%)
		Available locally	5 (41.7%)
		Available in practice	9 (75.0%)
		Not available	1 (8.3%)
		Total valid response	12 (100.0%)

Type of Treatment	Question	Response/time	Ophthalmologist
	What is the average amount of time your patients wait for a consultation appointment? (weeks)	Total missing	3
		Total valid numeric response (n)	8 (80.0%)
		Mean	2.8
		SD	1.4
		Median	3.0
		Min	1
		Max	4
		Don't know/not sure	1 (10.0%)
		Not applicable	1 (10.0%)
		Total valid response	10 (100.0%)
		Total missing	5
	What is the average amount of time your patients wait for a first treatment?(weeks)	Total valid numeric response (n)	8 (80.0%)
		Mean	2.4
		SD	1.4
		Median	2.0
		Min	1
		Max	4
		Don't know/not sure	1 (10.0%)
		Not applicable	1 (10.0%)
		Total valid response	10 (100.0%)
		Total missing	5
	What is the average amount of time your patients wait for a second treatment?(weeks)	Total valid numeric response (n)	9 (81.8%)
		Mean	4.4
		SD	4.4
		Median	3.0
		Min	1
		Max	12

Type of Treatment	Question	Response/time	Ophthalmologist
		Don't know/not sure	1 (9.1%)
		Not applicable	1 (9.1%)
		Total valid response	11 (100.0%)
		Total missing	4
Complex vitreo-retinal surgery	Is the treatment available?	Available within country	3 (25.0%)
		Available locally	5 (41.7%)
		Available in practice	9 (75.0%)
		Not available	1 (8.3%)
		Total valid response	12 (100.0%)
		Total missing	3
	What is the average amount of time your patients wait for a consultation appointment? (weeks)	Total valid numeric response (n)	8 (80.0%)
		Mean	2.6
		SD	1.7
		Median	2.0
		Min	1
		Max	6
		Don't know/not sure	1 (10.0%)
		Not applicable	1 (10.0%)
		Total valid response	10 (100.0%)
		Total missing	5
	What is the average amount of time your patients wait for a first treatment?(weeks)	Total valid numeric response (n)	8 (80.0%)
		Mean	2.6
		SD	1.7
		Median	2.0
		Min	1
		Max	6

Type of Treatment	Question	Response/time	Ophthalmologist
	What is the average amount of time your patients wait for a second treatment?(weeks)	Don't know/not sure	1 (10.0%)
		Not applicable	1 (10.0%)
		Total valid response	10 (100.0%)
		Total missing	5
		Total valid numeric response (n)	8 (80.0%)
		Mean	4.3
		SD	4.9
		Median	3.0
		Min	1
		Max	16
		Don't know/not sure	1 (10.0%)
		Not applicable	1 (10.0%)
		Total valid response	10 (100.0%)
		Total missing	5

#### PT 4.6

Question	Response	Ophthalmologist
Do you personally administer treatment for diabetic retinopathy?	Yes	12 (100.0%)
	Total valid response	12 (100.0%)
	Total missing	3
Who administer it?	Total missing	15

#### PT 4.7

Question	Response	Ophthalmologist
Do any of the following influence how you treat diabetic retinopathy or diabetic macular edema?	Diabetes duration	5 (41.7%)
	Patient's age	1 (8.3%)
	Presence of comorbidities such	6 (50.0%)

Question	Response	Ophthalmologist
	as hypertension, etc.	
	High glucose levels	5 (41.7%)
	Ability or inability to pay	4 (33.3%)
	Insurance restrictions	2 (16.7%)
	Patient educational level	2 (16.7%)
	Patient adherence to recommendations	3 (25.0%)
	None of the above	2 (16.7%)
	Not applicable	1 (8.3%)
	Total valid response	12 (100.0%)
	Total missing	3

#### PT 4.8

Question	Response	Ophthalmologist
Do you treat diabetic retinopathy and diabetic macular edema based on:	Visual outcome	3 (25.0%)
	Both	8 (66.7%)
	Other	1 (8.3%)
	Total Valid Response	12 (100.0%)
	Total missing	3

#### PT 4.9

Question	Response	Ophthalmologist
How are your patients with diabetes screened for diabetic eye disease?	Fundoscopy undilated	3 (25.0%)
	Fundoscopy dilated	9 (75.0%)
	Retinal photo	8 (66.7%)
	Optical Coherence Tomography	7 (58.3%)
	Fluorescein Angiography	2 (16.7%)
	Total valid response	12 (100.0%)
	Total missing	3

#### PT 4.10

Question	Response	Ophthalmologist
In your opinion, do the majority of your patients present:	In time for screening	3 (25.0%)
	When visual problems have already occurred	9 (75.0%)
	Total Valid Response	12 (100.0%)
	Total missing	3

#### PT 4.11

Question	Response	Ophthalmologist
Have you received training specifically on treatment and diagnosis of diabetic retinopathy and/or clinically significant diabetic macular edema?	Yes	11 (91.7%)
	No	1 (8.3%)
	Total valid response	12 (100.0%)
	Total missing	3
If yes, When was your last training?	Five or more years ago	3 (27.3%)
	Greater than 1 year ago but less than 5 years	5 (45.5%)
	Within the past year	3 (27.3%)
	Total valid response	11 (100.0%)
	Total missing	4

#### PT 4.12

Question	Response	Ophthalmologist
Would you be interested in online education and certification on DME, Angiogenesis and Anti-VEGF therapies?	Yes	10 (83.3%)
	No	2 (16.7%)
	Total Valid Response	12 (100.0%)
	Total missing	3

#### PT 4.13

Question	Response	Ophthalmologist
How is outreach for screening for diabetic eye disease done in your main practice?	Health fairs for all	5 (41.7%)



Question	Response	Ophthalmologist
	Health fairs for people with diabetes	5 (41.7%)
	Mobile screening centers	4 (33.3%)
	At vision centers	5 (41.7%)
	Other	2 (16.7%)
	Not done	2 (16.7%)
	Total valid response	12 (100.0%)
	Total missing	3

#### PT 4.14

Question	Response	Ophthalmologist
What do you perceive to be the greatest challenges for improving patient outcomes in diabetic eye disease?	Reimbursement/restrictions on approved therapy	5 (41.7%)
	Late diagnosis	8 (66.7%)
	Referral pathways	5 (41.7%)
	Limited access to patient education on diabetic retinopathy and diabetic macular edema	9 (75.0%)
	No universal guidelines on referral/screening	1 (8.3%)
	Government/insurance not able to cover patient costs	5 (41.7%)
	Multi-disciplinary team integration is poor	3 (25.0%)
	Ineffective screening services	6 (50.0%)
	Total valid response	12 (100.0%)
	Total missing	3

#### EXP 1

Question	Response	Without DED (%)	With DED (%)	With DME (%)
Which of the following complications of diabetes do you have?	Kidney disease	5 (7.4%)	6 (19.4%)	1 (11.1%)
	Loss of feeling in hands or toes (neuropathy)	8 (11.8%)	3 (9.7%)	5 (55.6%)

Question	Response	Without DED (%)	With DED (%)	With DME (%)
	Vision loss	6 (8.8%)	20 (64.5%)	6 (66.7%)
	Amputation	0 (0.0%)	3 (9.7%)	3 (33.3%)
	Broken bones or fractures	0 (0.0%)	1 (3.2%)	1 (11.1%)
	Foot ulcers	4 (5.9%)	0 (0.0%)	1 (11.1%)
	Cardiovascular disease/Stroke	4 (5.9%)	3 (9.7%)	0 (0.0%)
	Other	1 (1.5%)	0 (0.0%)	1 (11.1%)
	None	41 (60.3%)	6 (19.4%)	0 (0.0%)
	Don't know/Not sure	3 (4.4%)	0 (0.0%)	0 (0.0%)
	Total Valid Response	68 (100.0%)	31 (100.0%)	9 (100.0%)
	Total missing	2	0	0

NB [1]: Without DED = respondents who did not select "Yes" for both DED and DME.

NB [2]: DED = respondents with DED = "Yes" minus respondents with DME = "Yes".

NB [3]: DME = respondents with DME = "Yes".

NB [4]: Percentages within groups are calculated from non-missing data for that question.

## EXP 2

Limitations	Without DED n (%)	With DED n (%)	With DME n (%)
Limited in any way in any activities because of impairment or health problem	16 (23.5%)	8 (26.7%)	2 (22.2%)
Impairment or health problem			
Walking problem	8 (88.9%)	0 (0.0%)	1 (50.0%)
Hypertension/high blood pressure	7 (87.5%)	4 (100.0%)	0 (0.0%)
Arthritis/rheumatism	5 (83.3%)	0 (0.0%)	1 (100.0%)
Diabetes	7 (77.8%)	7 (100.0%)	1 (50.0%)
Eye/vision problem	6 (75.0%)	5 (100.0%)	1 (50.0%)
Fractures, bone/joint injury	3 (75.0%)	0 (0.0%)	0 (0.0%)
Hearing problem	3 (75.0%)	0 (0.0%)	0 (0.0%)
Stroke problem	2 (66.7%)	0 (0.0%)	0 (0.0%)
Cancer	2 (50.0%)	0 (0.0%)	0 (0.0%)
Heart problem	2 (50.0%)	0 (0.0%)	0 (0.0%)
Back or neck problem	1 (33.3%)	0 (0.0%)	0 (0.0%)
Lung/breathing problem	0 (0.0%)	0 (0.0%)	1 (100.0%)

NB [1]: Without DED = respondents who did not select "Yes" for both DED and DME.

NB [2]: DED = respondents with DED = "Yes" minus respondents with DME = "Yes".

NB [3]: DME = respondents with DME = "Yes".

NB [4]: Percentages within groups are calculated from non-missing data for that question.

### EXP 3

Health Status	Without DED (%)	With DED (%)	With DME (%)
Self-rated health: Good	34 (50.7%)	18 (60.0%)	5 (55.6%)
Self-rated health: Poor	33 (49.3%)	12 (40.0%)	4 (44.4%)
Physically unhealthy days	9 (15.8%)	4 (16.7%)	0 (0.0%)
Mentally unhealthy days	3 (5.1%)	2 (7.4%)	1 (11.1%)
Unhealthy days	9 (16.4%)	4 (16.7%)	1 (12.5%)
Activity limitation days	5 (29.4%)	1 (16.7%)	1 (50.0%)

NB [1]: Without DED = respondents who did not select "Yes" for both DED and DME.

NB [2]: DED = respondents with DED = "Yes" minus respondents with DME = "Yes".

NB [3]: DME = respondents with DME = "Yes".

### EXP 4

Item	Response	All respondents	Respondents with Type I diabetes	Respondents with Type II diabetes
How do you manage your diabetes?	Diet	73 (67.0%)	1 (100.0%)	37 (72.5%)
	Oral medicine	90 (82.6%)		41 (80.4%)
	Exercise	25 (22.9%)		15 (29.4%)
	Insulin	45 (41.3%)		23 (45.1%)
	Natural/Herbal medicine	8 (7.3%)		6 (11.8%)

NB [1]: Percentages within groups are calculated from non-missing data for that question.

### EXP 5.1

Item	Response	Without DED (%)	With DED (%)	With DME (%)
Are you currently working?	Working for pay	19 (27.9%)	5 (16.7%)	4 (44.4%)
	Working without pay at home (e.g. housework, farming)	5 (7.4%)	2 (6.7%)	1 (11.1%)
	Retired	21 (30.9%)	7 (23.3%)	2 (22.2%)
	Not working	23 (33.8%)	16 (53.3%)	2 (22.2%)
	Total Valid Response	68 (100.0%)	30 (100.0%)	9 (100.0%)
	Total missing	2	1	0

Item	Response	Without DED (%)	With DED (%)	With DME (%)
Do you receive assistance from the government?	Income assistance	4 (6.1%)	4 (14.3%)	5 (55.6%)
	Medical assistance	16 (24.2%)	11 (39.3%)	0 (0.0%)
	Housing assistance	0 (0.0%)	0 (0.0%)	1 (11.1%)
	Pension assistance	14 (21.2%)	5 (17.9%)	1 (11.1%)
	None of the above	35 (53.0%)	12 (42.9%)	2 (22.2%)
	Total valid response	66 (100.0%)	28 (100.0%)	9 (100.0%)
	Total missing	4	3	0
Did you have trouble paying for food at anytime during the past year?	Yes	6 (9.2%)	1 (3.3%)	2 (22.2%)
	No	59 (90.8%)	29 (96.7%)	7 (77.8%)
	Total Valid Response	65 (100.0%)	30 (100.0%)	9 (100.0%)
	Total missing	5	1	0

NB [1]: Without DED = respondents who did not select "Yes" for both DED and DME.

NB [2]: DED = respondents with DED = "Yes" minus respondents with DME = "Yes".

NB [3]: DME = respondents with DME = "Yes".

NB [4]: Percentages within groups are calculated from non-missing data for that question.

#### EXP 5.2: Age group 18-39 years

Item	Response	Without DED (%)	With DED (%)	With DME (%)
Are you currently working?	Working for pay	2 (66.7%)	1 (50.0%)	1 (100.0%)
	Not working	1 (33.3%)	1 (50.0%)	0 (0.0%)
	Total Valid Response	3 (100.0%)	2 (100.0%)	1 (100.0%)
Do you receive assistance from the government?	Income assistance	1 (33.3%)	0 (0.0%)	1 (100.0%)
	Medical assistance	2 (66.7%)	1 (50.0%)	0 (0.0%)
	None of the above	1 (33.3%)	1 (50.0%)	0 (0.0%)
	Total valid response	3 (100.0%)	2 (100.0%)	1 (100.0%)

Item	Response	Without DED (%)	With DED (%)	With DME (%)
	Total missing	0	0	0
Did you have trouble paying for food at anytime during the past year?	Yes	1 (33.3%)	0 (0.0%)	1 (100.0%)
	No	2 (66.7%)	2 (100.0%)	0 (0.0%)
	Total Valid Response	3 (100.0%)	2 (100.0%)	1 (100.0%)

NB [1]: Without DED = respondents who did not select "Yes" for both DED and DME.

NB [2]: DED = respondents with DED = "Yes" minus respondents with DME = "Yes".

NB [3]: DME = respondents with DME = "Yes".

### EXP 5.3: Age group 40-59 years

Item	Response	Without DED (%)	With DED (%)	With DME (%)
Are you currently working?	Working for pay	14 (51.9%)	4 (30.8%)	3 (60.0%)
	Working without pay at home (e.g. housework, farming)	3 (11.1%)	1 (7.7%)	1 (20.0%)
	Retired	3 (11.1%)	2 (15.4%)	0 (0.0%)
	Not working	7 (25.9%)	6 (46.2%)	1 (20.0%)
	Total Valid Response	27 (100.0%)	13 (100.0%)	5 (100.0%)
	Total missing	2	0	0
Do you receive assistance from the government?	Income assistance	2 (7.4%)	2 (16.7%)	3 (60.0%)
	Medical assistance	5 (18.5%)	5 (41.7%)	0 (0.0%)
	Housing assistance	0 (0.0%)	0 (0.0%)	1 (20.0%)
	Pension assistance	1 (3.7%)	2 (16.7%)	0 (0.0%)
	None of the above	20 (74.1%)	5 (41.7%)	1 (20.0%)
	Total valid response	27 (100.0%)	12 (100.0%)	5 (100.0%)
	Total missing	2	1	0
Did you have trouble paying for food at anytime during the past year?	Yes	3 (11.5%)	1 (7.7%)	1 (20.0%)
	No	23 (88.5%)	12 (92.3%)	4 (80.0%)
	Total Valid Response	26 (100.0%)	13 (100.0%)	5 (100.0%)

Item	Response	Without DED (%)	With DED (%)	With DME (%)
	Total missing	3	0	0

NB [1]: Without DED = respondents who did not select "Yes" for both DED and DME.

NB [2]: DED = respondents with DED = "Yes" minus respondents with DME = "Yes".

NB [3]: DME = respondents with DME = "Yes".

#### EXP 5.4: Age group 60-79 years

Item	Response	Without DED (%)	With DED (%)	With DME (%)
Are you currently working?	Working for pay	3 (7.9%)	0 (0.0%)	0 (0.0%)
	Working without pay at home (e.g. housework, farming)	2 (5.3%)	1 (6.7%)	0 (0.0%)
	Retired	18 (47.4%)	5 (33.3%)	2 (66.7%)
	Not working	15 (39.5%)	9 (60.0%)	1 (33.3%)
	Total Valid Response	38 (100.0%)	15 (100.0%)	3 (100.0%)
	Total missing	0	1	0
Do you receive assistance from the government?	Income assistance	1 (2.8%)	2 (14.3%)	1 (33.3%)
	Medical assistance	9 (25.0%)	5 (35.7%)	0 (0.0%)
	Pension assistance	13 (36.1%)	3 (21.4%)	1 (33.3%)
	None of the above	14 (38.9%)	6 (42.9%)	1 (33.3%)
	Total valid response	36 (100.0%)	14 (100.0%)	3 (100.0%)
	Total missing	2	2	0
Did you have trouble paying for food at anytime during the past year?	Yes	2 (5.6%)	0 (0.0%)	0 (0.0%)
	No	34 (94.4%)	15 (100.0%)	3 (100.0%)
	Total Valid Response	36 (100.0%)	15 (100.0%)	3 (100.0%)
	Total missing	2	1	0

NB [1]: Without DED = respondents who did not select "Yes" for both DED and DME.

NB [2]: DED = respondents with DED = "Yes" minus respondents with DME = "Yes".

NB [3]: DME = respondents with DME = "Yes".

#### EXP 5.5: Age group 80+ years

Item	Response	Without DED (%)	With DED (%)	With DME (%)
Are you currently working?		0 (0.0%)	0 (0.0%)	0 (0.0%)
Do you receive assistance from the government?	Total valid response	0	0	0
	Total missing	0	0	0
Did you have trouble paying for food at anytime during the past year?		0 (0.0%)	0 (0.0%)	0 (0.0%)

NB [1]: Without DED = respondents who did not select "Yes" for both DED and DME.

NB [2]: DED = respondents with DED = "Yes" minus respondents with DME = "Yes".

NB [3]: DME = respondents with DME = "Yes".

## EXP 6

Group	Subgroup	All respondents	Type 1 diabetes	Type 2 diabetes	With DED (%)	With DME (%)
All respondents		110 (100%)	1 (0.9%)	51 (46.4%)	31 (28.2%)	9 (8.2%)
Gender	Male	34 (32.1%)	0 (0.0%)	13 (38.2%)	11 (32.4%)	3 (8.8%)
	Female	72 (67.9%)	1 (1.4%)	35 (48.6%)	19 (26.4%)	6 (8.3%)
	Total Missing	4	0	3	1	0
Age	18-39 yrs	6 (5.5%)	1 (16.7%)	5 (83.3%)	2 (33.3%)	1 (16.7%)
	40-59 yrs	47 (42.7%)	0 (0.0%)	24 (51.1%)	13 (27.7%)	5 (10.6%)
	60-79 yrs	57 (51.8%)	0 (0.0%)	22 (38.6%)	16 (28.1%)	3 (5.3%)
Time since diagnosis	Within the last year	6 (5.5%)	1 (16.7%)	4 (66.7%)	0 (0.0%)	0 (0.0%)
	1 - 5 years ago	33 (30.0%)	0 (0.0%)	16 (48.5%)	7 (21.2%)	3 (9.1%)
	6 - 10 years ago	26 (23.6%)	0 (0.0%)	10 (38.5%)	4 (15.4%)	3 (11.5%)
	11 - 15 years ago	21 (19.1%)	0 (0.0%)	7 (33.3%)	9 (42.9%)	0 (0.0%)
	16 - 20 years ago	12 (10.9%)	0 (0.0%)	7 (58.3%)	5 (41.7%)	1 (8.3%)
	21 years ago or longer	11 (10.0%)	0 (0.0%)	7 (63.6%)	6 (54.5%)	1 (9.1%)
	Don't know/Not sure	1 (0.9%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (100.0%)

Group	Subgroup	All respondents	Type 1 diabetes	Type 2 diabetes	With DED (%)	With DME (%)
Control of Diabetes	Controlled	72 (66.7%)	1 (1.4%)	25 (34.7%)	19 (26.4%)	6 (8.3%)
	Not controlled	33 (30.6%)	0 (0.0%)	21 (63.6%)	11 (33.3%)	3 (9.1%)
	Don't know/Not sure	3 (2.8%)	0 (0.0%)	3 (100.0%)	1 (33.3%)	0 (0.0%)
	Total Missing	2	0	2	0	0

NB [1]: DED = respondents with DED = "Yes" minus respondents with DME = "Yes".

NB [2]: DME = respondents with DME = "Yes".

NB [3]: Percentages within groups are calculated from non-missing data for that question.

## EXP 7

Question	Response	With DED n (%)	With DME n (%)
Have you had any treatment for diabetic eye disease?	Yes	21 (67.7%)	7 (87.5%)
	No	9 (29.0%)	1 (12.5%)
	Don't know/Not sure	1 (3.2%)	0 (0.0%)
	Total valid response	31 (100.0%)	8 (100.0%)
	Total missing	0	1
What treatment did you receive?	Laser	17 (85.0%)	7 (100.0%)
	Anti-VEGF	2 (10.0%)	3 (42.9%)
	Surgery	1 (5.0%)	0 (0.0%)
	Other	2 (10.0%)	0 (0.0%)
	Total valid response	20 (100.0%)	7 (100.0%)
	Total missing	11	2
Did you complete the treatment?	Yes	16 (80.0%)	6 (85.7%)
	Still receiving treatment	3 (15.0%)	1 (14.3%)
	Don't know/Not sure	1 (5.0%)	0 (0.0%)
	Total valid response	20 (100.0%)	7 (100.0%)
	Total missing	11	2
Do you feel that the treatment worked?	Yes, and vision improved	13 (65.0%)	3 (42.9%)
	Yes, but vision stayed the	3 (15.0%)	3 (42.9%)



Question	Response	With DED n (%)	With DME n (%)
	same		
	No	1 (5.0%)	1 (14.3%)
	Still waiting to know	2 (10.0%)	0 (0.0%)
	Don't know/Not sure	1 (5.0%)	0 (0.0%)
	Total valid response	20 (100.0%)	7 (100.0%)
	Total missing	11	2
What is/are the reason(s) that you did not complete the treatment?	Total valid response	0 (0.0%)	0 (0.0%)
	Total missing	31	9
What are the reason(s) that you have not had treatment for diabetic eye disease?	My doctor did not recommend any treatment	8 (88.9%)	1 (100.0%)
	Other	1 (11.1%)	0 (0.0%)
	Total valid response	9 (100.0%)	1 (100.0%)
	Total missing	22	8

NB [1]: DED = respondents with DED = "Yes" minus respondents with DME = "Yes".

NB [2]: DME = respondents with DME = "Yes".

NB [3]: Percentages within groups are calculated from non-missing data for that question.



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