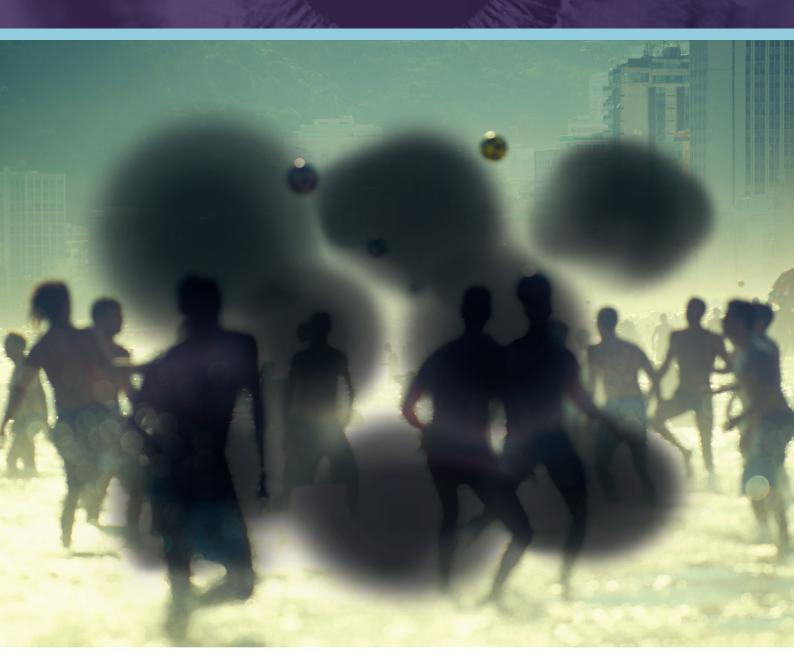


The Diabetic Retinopathy Barometer Report

## Brazil











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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** 



## 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 Brazil.

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, 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 DED, 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 so as to enable people with diabetes to maintain their health and ensure that the contributions 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 the 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.

In the global analysis, respondents from each country were grouped into regions as defined by the WHO and into the WBIGs.

#### **Study Populations**

The people with diabetes who participated in the patient survey were self-selected, predominantly from patient organisations. Therefore, this population 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 principles should be applied when interpreting the results.

Even though the sample is not representative of the broader population of adults 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 adults with diabetes and health care professionals around the world. This study provides a rich resource for generating unique insights into real-life experiences, 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% 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 types of professionals.



## Introduction **Brazil Study**

#### **Demographic Characteristics**<sup>1</sup>

Brazil is estimated to be the most populous country in Latin America with a population of approximately 209.5 million.

Although Brazil currently has a relatively young population with ~23% of its population under the age of 15 and only 8% of its population 65 and older, this is predicted to drastically change in the decades to come despite its increasing population.

By 2050, it is projected that those under the age of 15 will only make up 15% of the total population while those over the age of 65 will make up 22% of the total population. This means that in just over thirty years the population for those aged 65 or older will increase by 218%, reaching an all-time high of approximately 54.2 million.

#### **Diabetes Profile**

There are 415 million people with diabetes in the world and approximately 29.6 million people in the South and Central America Region. By 2040, this number is expected to rise to 48.8 million.

Twenty countries and territories comprise the South and Central American region and although Brazil's economic growth plateaued recently, most other countries in the region experienced substantial economic growth in 2015.

In the region, 9.4% (29.6 million) people were living with diabetes and out of the 29.6 million, 39% are undiagnosed. It is important to note that over 82% of people with diabetes live in urban environments and 81% are living in middle-income countries.

Brazil has the highest number of people living with diabetes in the South and Central America region at ~14.3 million (12,910.8-

15,752.4‡), which accounts to ~48% of people living with diabetes in this region. Globally, Brazil is placed fourth in the world for the number of adults living with diabetes. Brazil will continue to be in the top 10 countries for the highest adult population with diabetes in 2040 at an estimated 23.3 million (21.0-25.9‡).

Brazil is also the sixth country in the world for the number of people with impaired glucose tolerance at ~11.0 million people and will continue to be in the top ten countries in 2040 with an estimated 16.7 million people with impaired glucose intolerance. It is important to note that Brazil is fifth in the world for diabetes-related health expenditures at 22 billion USD and expected to increase to an estimated 36 billion USD by 2040.

Brazil's national prevalence (20-79 years) is 10.2% (9.3-11.3‡) and the diabetes age-adjusted comparative prevalence is 10.4% (9.4-11.5‡). The estimated number of undiagnosed cases was ~5.7 million (6,690.4-8,162.9‡). Deaths attributed to diabetes in Brazil in 2015 were 130,712, which accounts to over half (~53%) of the diabetes-related deaths experienced in this region.

#### **Study Populations: Brazil**

As reported by 139 adults with diabetes in Brazil, 27% of respondents have been diagnosed with DED and a further 6.5% with DME.

One hundred and twenty-four health care professionals completed the survey in Brazil. Of these, 25 were diabetes specialist providers (20%), 78 were ophthalmologists (63%), and six were primary care providers (4.8%). The remaining respondents were optometrists, nurses, health educators or other types of professionals.

### The DR Barometer Study: **Brazil Overview**

The DR Barometer study was conducted in 41 countries. In Brazil, 139 adults with diabetes and 124 health care professionals provided new information about the experiences of living with, managing and treating diabetes, DR and DME.

28%

of patients said that **cost** was a barrier to eye exams



54%

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



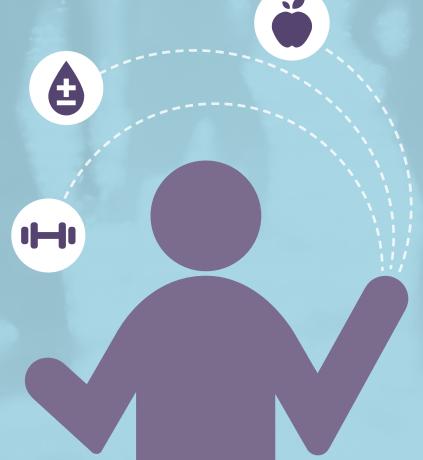








of respondents said their vision impairment due to DR or DME made it difficult to manage their diabetes







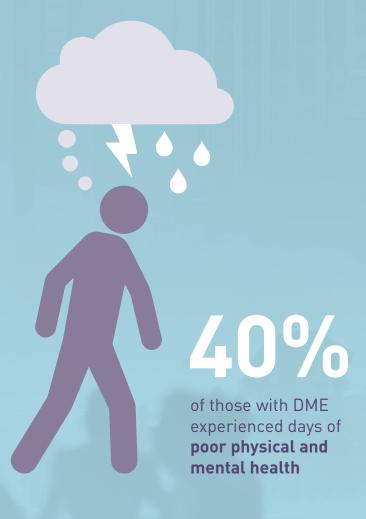
91%

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



6%

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



28%

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



## Brazil DR Barometer Findings:

#### **Adults with Diabetes**

### Key Demographic Characteristics

One hundred and thirty-nine adults with diabetes (patients) completed the patients' survey in Brazil: 69% were female and 31% were male. Ninety-seven percent lived in an urban setting and 3.3% resided in a non-urban setting (see Appendix Table 4.2).

The education levels of all respondents was as follows: 2.5% did not complete primary school, 3.3% were educated to a primary school level, and 27% to a secondary school level, 34% to a college or university level, and 33% to a graduate or post-graduate level (see Appendix Table 4.3).

Sixty-four percent of all respondents were in paid employment, 12% were retired and 12% stated they were not working (see Appendix Table 4.4).

Most respondents (52%) were aged between 18 and 39 years (31% were 40-59 years, 15% were 60-79 years and 2.2% were 80 years plus). Eighty-three percent were of traditional working age (18-59 years) (see Table 1).

Of the respondents in Brazil, 57% had been diagnosed with type 1 diabetes and 40% with type 2 diabetes. A further 2.9% of respondents were either unsure of or did not know their type of diabetes (see Appendix Table 2.1).

Six percent of respondents were diagnosed with diabetes within the last year, 1 - 5 years ago (24%), 6 - 10 years ago (20%), 11 - 15 years ago (14%), 16 - 20 years ago (17%), and 21 years ago or more (19%) (see Appendix Table 2.2).

A younger population was more likely to be associated with type 1 diabetes, which was the opposite of those with type 2 diabetes which tended to be an older population. Amongst 18 to 39-year-olds, 82% had type 1 and 18% had type 2 diabetes. In the 40-59 year age group, 33% had type 1 and 63% had type 2 diabetes, 29% of 60-79-year-olds had type 1 diabetes and 71% had type 2.

Twenty-seven percent of respondents (n=38) have reported they have been diagnosed with DED and a further 6.5% (n=9) with DME.

In the 18-39 year age group, 32% had DED and 8.3% had DME. For the 40-59 year age group this decreased to 14% for DED and 2.3% for DME, in the 60-79 year age group it was 38% and 9.5% respectively.

A particularly important trend noted in the findings as that the longer the time since diabetes was diagnosed, the greater the likelihood for DED and DME to be detected.

In respondents diagnosed 1-5 years ago 15.2% had DED and 6.1% were diagnosed with DME. For respondents diagnosed 6-10 years ago, the proportion with DED increased to 32% however none of the respondents in this subgroup had DME. In those diagnosed 16-20 years ago, 35% had DED and 8.7% had DME. Of note is the finding that 39% of those who had been diagnosed 21 years ago or more had DED and 19% had DME.

While most (60%) respondents reported that their diabetes was well controlled, 39% felt that their diabetes was not well controlled. For those whose diabetes was controlled, 27% had DED and 3.8% had DME. In those whose diabetes was not controlled a 33% had DED and 12% 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
All respondents		139 (100.0%)	79 (56.8%)	56 (40.3%)	38 (27.3%)	9 (6.5%)
Gender	Male	37 (30.6%)	13 (35.1%)	24 (64.9%)	10 (27.0%)	3 (8.1%)
	Female	84 (69.4%)	56 (66.7%)	26 (31.0%)	28 (33.3%)	6 (7.1%)
	Total Missing	18	10	6	0	0
Age	18-39 yrs.	72 (51.8%)	59 (81.9%)	13 (18.1%)	23 (31.9%)	6 (8.3%)
	40-59 yrs.	43 (30.9%)	14 (32.6%)	27 (62.8%)	6 (14.0%)	1 (2.3%)
	60-79 yrs.	21 (15.1%)	6 (28.6%)	15 (71.4%)	8 (38.1%)	2 (9.5%)
	80 yrs. plus	3 (2.2%)	0 (0.0%)	1 (33.3%)	1 (33.3%)	0 (0.0%)
Time since diagnosis	Within the last year	8 (5.8%)	2 (25.0%)	5 (62.5%)	3 (37.5%)	0 (0.0%)
	1 - 5 yrs.	33 (23.9%)	12 (36.4%)	21 (63.6%)	5 (15.2%)	2 (6.1%)
	6 - 10 yrs.	28 (20.3%)	11 (39.3%)	16 (57.1%)	9 (32.1%)	0 (0.0%)
	11 - 15 yrs.	19 (13.8%)	13 (68.4%)	6 (31.6%)	3 (15.8%)	0 (0.0%)
	16 - 20 yrs.	23 (16.7%)	17 (73.9%)	5 (21.7%)	8 (34.8%)	2 (8.7%)
	21 yrs. plus	26 (18.8%)	23 (88.5%)	3 (11.5%)	10 (38.5%)	5 (19.2%)
	Don't know/ Not sure	1 (0.7%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	Total Missing	1	1	0	0	0
Control of Diabetes	Controlled	79 (59.8%)	39 (49.4%)	39 (49.4%)	21 (26.6%)	3 (3.8%)
	Not controlled	51 (38.6%)	35 (68.6%)	14 (27.5%)	17 (33.3%)	6 (11.8%)
	Don't know/ Not sure	2 (1.5%)	0 (0.0%)	1 (50.0%)	0 (0.0%)	0 (0.0%)
	Total Missing	7	5	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

Ninety-eight percent of those surveyed saw a health care professional for their diabetes, with 70% seeing a diabetes specialist (average number of visits was 3.5 times per year) and 27% seeing a general/family doctor (average number of visits was 2.5 times per year) (see Appendix Table 2.3.1 and 2.3.2).

Adults with diabetes were informed about their condition through a variety of channels. Ninety-one percent received information from a doctor or nurse, 31% from the internet, and 29% from a nutritionist or dietician (see Table 2 and Appendix Table 2.4).

Table 2: Source of information regarding diabetes

Information Source	All Respondents (n=135)
Doctor or nurse	123 (91.1%)
Internet	42 (31.1%)
Nutritionist or dietician	39 (28.9%)
Diabetes organisation or other health organisation	32 (23.7%)
Family/Friends/Neighbours	23 (17.0%)
Social media (e.g. Facebook, Twitter, blogs)	23 (17.0%)
Health educator	20 (14.8%)
TV/Radio/Newspaper/Magazines	20 (14.8%)
Pharmacist	4 (3.0%)
None of the above	5 (3.7%)

A range of strategies was used by respondents to manage their diabetes. For those with type 1 diabetes, apart from insulin, 60% managed their diabetes with diet, 52% with exercise, and 17% with oral medicine. Of the respondents with type 2 diabetes, 78% managed their condition with diet, 67% with oral medicine, 40% with exercise, and 40% with insulin.

Twenty-four percent of respondents were enrolled in diabetes management programmes. Seventy-eight percent of respondents said the programme included 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 experienced included blood glucose checks and undilated eye checks. Of the respondents that had eye checks (87%), these occurred at the following intervals: less than 6 months (42%), 6 - 12 months (27%), and greater than 12 months (16%) (see Appendix Table 2.7).

The main challenges in controlling diabetes cited by respondents were: it was too hard to eat the right things (59%), the high cost of care (33%), there were too many other things to do (18%), there were long wait times for an appointment to see their doctor or specialist (17%), and not having insurance (11%) (see Appendix Table 2.9).

Free or low cost medicines or monitoring materials (66%), support from family or friends (49%), health education and information (44%), coordination of healthcare and services by a professional (15%), and support groups (9.3%) were identified as important to improving the management of a person's diabetes. Seven percent stated that none of the services listed helped them to better manage their diabetes (see Appendix Table 2.10).



### Nature and Information about Complications

Ninety-two percent of respondents were aware of vision loss and other complications, such as: amputation (85%), kidney disease (72%), and cardiovascular disease/stroke (72%) were also associated with diabetes (see Appendix Table 2.11).

Respondents were most concerned about: vision loss (48%), cardiovascular disease/ stroke (20%), amputation (15%), and kidney disease (15%) (see Appendix Table 2.12).

Fifty-five percent of respondents reported that they had no complications of diabetes. However, of those who did report complications: 25% had vision loss, neuropathy (6.6%), kidney disease (4.9%), cardiovascular disease or stroke (3.3%), and foot ulcers (1.6%) (see Figure 1 and Appendix Table 2.13).

The frequency of cardiovascular disease or stroke increased from 2.6% in those without DED to 11% in those with DME, similar to neuropathy. The frequency of other complications also increased but the number of respondents was small (see Table 3 and Appendix EXP 1).

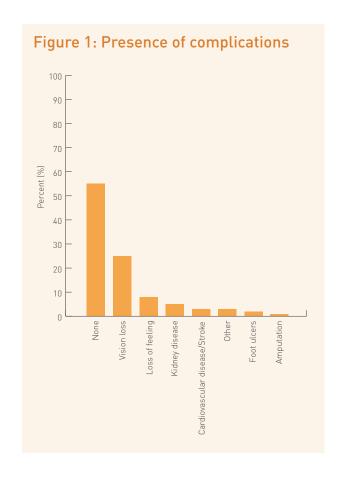


Table 3: Presence of complications without DED, with DED or DME

Complication	Without DED (n=77)	With DED (n=36)	With DME (n=9)
Any	20 (26%)	28 (77.8%)	7 (77.8%)
Vision loss	5 (6.5%)	19 (52.8%)	7 (77.8%)
Kidney disease	1 (1.3%)	5 (13.9%)	0 (0.0%)
Loss of feeling in hands or toes (neuropathy)	3 (3.9%)	4 (11.1%)	1 (11.1%)
Cardiovascular disease/Stroke	2 (2.6%)	1 (2.8%)	1 (11.1%)
Foot ulcers	1 (1.3%)	1 (2.8%)	0 (0.0%)
Amputation	1 (1.3%)	0 (0.0%)	0 (0.0%)
Other	2 (2.6%)	2 (5.6%)	0 (0.0%)
None	57 (74.0%)	8 (22.2%)	2 (22.2%)

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

While eighty-eight percent of respondents stated that eye complications were discussed with their health care professionals, more than a quarter (28%) either never discussed eye complications with their doctor (11%) or did so only after the onset of symptoms (17%). The frequency of regular discussions varied from every visit (37%), multiple times a year (14%), and once a year (20%) (see Appendix Table 2.14).

Eighty percent of respondents said that they did what they could to prevent vision problems (e.g. get routine screenings, visit specialists), yet myths and perceptions around vision changes and preventions were evident with 12% reporting to either not make any special effort to prevent vision problems or thought that vision problems were a normal part of ageing (see Appendix Table 2.15).

Seventy-four percent of all respondents received information about DR and DME with the doctor or nurse being the most common source (60%). A surprising finding was that one in four respondents did not receive such information from any of the sources listed (see Table 4 and Appendix Table 3.9).

Table 4: Source of information about DR and DME

Source	All respondents (n=113)
Doctor/Nurse	68 (60.2%)
Internet	26 (23.0%)
Diabetes organisation or other health organisation	10 (8.8%)
Family/Friends/ Neighbours	8 (7.1%)
Health educator	7 (6.2%)
TV/Radio/Newspaper/ Magazines	7 (6.2%)
None of the above	29 (25.7%)

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

Eighty-seven percent of the respondents reported having an eye exam for DED, with 72% reporting to have had an eye exam within the last year and a further 18% more than one year ago but less than two years ago. Thirty percent of respondents were aware of a government sponsored screening programme for DED (see Appendix Table 3.1 and 3.2).

Ninety-two percent of those surveyed thought they should have their eyes examined for DED once a year, seven respondents said that testing should only happen every two years, and one respondent said that testing should happen only when symptoms occur (see Appendix Table 3.4).

The biggest barriers to eye exams were: the expense of the eye exam (28%), there were long wait times for an appointment (25%), and the referral process was complicated or took too long (19%) (see Table 5 and Appendix 3.5).

Table 5: Barriers to eye examinations

They are expensive 29 (27.6%)  Long wait time for appointment 26 (24.8%)  Referral process is complicated or takes too long  Eye exams are not available near my home  Long wait time on the day of the visit  Limited access to diabetes specialists  Too many other things to do or worry about  Fear of treatment/results  Recommended treatments for eye problems are not available  Don't know much about my condition  I'm not likely to have eye complications  Clinics are too small or lack necessary equipment/staff  Burden on my family/friends  Other  29 (27.6%)  20 (19.0%)  17 (16.2%)  13 (12.4%)  11 (10.5%)  5 (4.8%)  5 (4.8%)  5 (4.8%)  4 (3.8%)  11 (10.5%)  11 (10.5%)  12 (4.8%)  13 (12.4%)  14 (10.5%)  15 (4.8%)  16 (4.8%)  17 (16.2%)  18 (10.5%)  19 (10.5%)  10 (10.5%)  10 (10.5%)  11 (10.5%)  12 (4.8%)  13 (12.4%)  14 (10.5%)  15 (4.8%)  16 (4.8%)  17 (16.2%)	Identified Barriers	All Respondents (n=105)
Referral process is complicated or takes too long  Eye exams are not available near my home  Long wait time on the day of the visit  Limited access to diabetes specialists  Too many other things to do or worry about  Fear of treatment/results  Recommended treatments for eye problems are not available  Don't know much about my condition  I'm not likely to have eye complications  Clinics are too small or lack necessary equipment/staff  Burden on my family/friends  20 (19.0%)  17 (16.2%)  18 (12.4%)  19 (10.5%)  11 (10.5%)  5 (4.8%)  5 (4.8%)  20 (19.0%)  14 (10.2%)  15 (4.8%)  16 (10.5%)  17 (16.2%)  18 (10.5%)  19 (10.5%)  10 (10.5%)  10 (10.5%)  11 (10.5%)	They are expensive	29 (27.6%)
or takes too long  Eye exams are not available near my home  Long wait time on the day of the visit  Limited access to diabetes specialists  Too many other things to do or worry about  Fear of treatment/results  Recommended treatments for eye problems are not available  Don't know much about my condition  I'm not likely to have eye complications  Clinics are too small or lack necessary equipment/staff  Burden on my family/friends  17 (16.2%)  13 (12.4%)  11 (10.5%)  5 (4.8%)  5 (4.8%)  5 (4.8%)  3 (2.9%)	Long wait time for appointment	26 (24.8%)
near my home  Long wait time on the day of the visit  Limited access to diabetes specialists  Too many other things to do or worry about  Fear of treatment/results  Recommended treatments for eye problems are not available  Don't know much about my condition  I'm not likely to have eye complications  Clinics are too small or lack necessary equipment/staff  Burden on my family/friends  13 (12.4%)  11 (10.5%)  5 (4.8%)  5 (4.8%)  5 (4.8%)  1 (3.8%)  1 (1.0%)	·	20 (19.0%)
the visit  Limited access to diabetes specialists  Too many other things to do or worry about  Fear of treatment/results  Recommended treatments for eye problems are not available  Don't know much about my condition  I'm not likely to have eye complications  Clinics are too small or lack necessary equipment/staff  Burden on my family/friends  11 (10.5%)  5 (4.8%)  5 (4.8%)  5 (4.8%)  4 (3.8%)  1 (1.0%)	,	17 (16.2%)
specialists  Too many other things to do or worry about  Fear of treatment/results  Recommended treatments for eye problems are not available  Don't know much about my condition  I'm not likely to have eye complications  Clinics are too small or lack necessary equipment/staff  Burden on my family/friends  1 (1.0%)	,	13 (12.4%)
worry about  Fear of treatment/results  Recommended treatments for eye problems are not available  Don't know much about my condition  I'm not likely to have eye complications  Clinics are too small or lack necessary equipment/staff  Burden on my family/friends  1 (1.0%)		11 (10.5%)
Recommended treatments for eye problems are not available  Don't know much about my condition  I'm not likely to have eye complications  Clinics are too small or lack necessary equipment/staff  Burden on my family/friends  5 (4.8%)  5 (4.8%)  5 (4.8%)  5 (4.8%)  1 (1.0%)		11 (10.5%)
eye problems are not available  Don't know much about my condition  I'm not likely to have eye complications  Clinics are too small or lack necessary equipment/staff  Burden on my family/friends  5 (4.8%)  4 (3.8%)  3 (2.9%)  1 (1.0%)	Fear of treatment/results	8 (7.6%)
condition  I'm not likely to have eye complications  Clinics are too small or lack necessary equipment/staff  Burden on my family/friends  5 (4.8%)  4 (3.8%)  3 (2.9%)  1 (1.0%)		5 (4.8%)
complications  Clinics are too small or lack necessary equipment/staff  Burden on my family/friends  4 (3.6%)  3 (2.9%)  1 (1.0%)	,	5 (4.8%)
necessary equipment/staff  Burden on my family/friends 1 (1.0%)		4 (3.8%)
, , , , , , , , , , , , , , , , , , , ,		3 (2.9%)
Other 28 (26.7%)	Burden on my family/friends	1 (1.0%)
	Other	28 (26.7%)

#### Treatment of Diabetic Eye Disease and Diabetic Macular Edema

Treatment was assessed separately in people with DED and in those with DME. For those with DED 90% (n=34) had received treatment and the most common treatment was laser treatment (67%). Of those who received treatment, 59% (n=20) completed their treatment, 27% (n=9) were currently still receiving treatment and 12% (n=4) did not complete the treatment. Eighty percent felt that treatment had been successful and either their vision had improved (67%) or had stayed the same (13%) (see Table 6).

Eighty-eight percent of patients with DME (n=7) had received treatment and the most common treatments were laser (86%) and anti-VEGF therapy (71%). Seventy-one percent felt that treatment had been successful and either their vision had improved (57%) or vision had stayed the same (14%). Two respondents (29%) were still waiting to know the outcome of their treatment.

All respondents with DME (n=9) said they would prefer proactive treatment to prevent further vision loss rather than reactive treatment 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=38)	With DME (n=8)
Have you had any treatment	Yes	34 (89.5%)	7 (87.5%)
for diabetic eye disease?	No	2 (5.3%)	1 (12.5%)
	Don't know/Not sure	2 (5.3%)	0 (0.0%)
What treatment did you	Laser	22 (66.7%)	6 (85.7%)
receive?	Anti-VEGF	10 (30.3%)	5 (71.4%)
	Surgery	1 (3.0%)	3 (42.9%)
	Other	2 (6.1%)	0 (0.0%)
Did you complete the	Yes	20 (58.8%)	3 (42.9%)
treatment?	No	4 (11.8%)	0 (0.0%)
	Still receiving treatment	9 (26.5%)	4 (57.1%)
	Don't know/Not sure	1 (2.9%)	0 (0.0%)
Do you feel that the	Yes, and vision improved	20 (66.7%)	4 (57.1%)
treatment worked?	Yes, but vision stayed the same	4 (13.3%)	1 (14.3%)
	Still waiting to know	5 (16.7%)	2 (28.6%)
	Don't know/Not sure	1 (3.3%)	0 (0.0%)
What is/are the reason(s)	Treatment was too expensive	1 (25.0%)	0 (0.0%)
that you did not complete the treatment?	Eye doctor was located too far away	1 (25.0%)	0 (0.0%)
the treatment:	Appointment times were not convenient	1 (25.0%)	0 (0.0%)
	I was fearful (scared) of treatment	2 (50.0%)	0 (0.0%)
What are the reason(s) that	My doctor did not recommend any treatment	1 (100.0%)	1 (100.0%)
you have not had treatment for diabetic eye disease?	Treatment is not accessible	0 (0.0%)	1 (100.0%)
ioi diabetic eye disease!	Still waiting for treatment	0 (0.0%)	1 (100.0%)
	Too expensive	0 (0.0%)	1 (100.0%)

NB [1]: DED = respondents with DED = "Yes" minus respondents with DME = "Yes"  $\alpha$ 

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

Seventy-one percent of those diagnosed with DED or DME reported that their vision was affected (17% significantly, 54% slightly) (see Appendix Table 3.6).

Ninety-one percent of these respondents reported vision issues impacted their daily lives. Ways in which their lives were affected included: driving a vehicle (61%), leisure activities or exercise (36%), household responsibilities, such as cooking or cleaning (33%), social interactions with family or friends (33%), working or keeping a job (21%), travelling (18%), and managing their underlying diabetes (6.1%) (see Table 7).

Table 7: Activities affected through vision impairment and loss

Have vision issues caused you to have difficulty with any of the following?	All Respondents (n=33)
Driving (a car/vehicle)	20 (60.6%)
Leisure activities/exercise	12 (36.4%)
Household responsibilities, such as cooking or cleaning	11 (33.3%)
Social interactions with family/ friends	11 (33.3%)
Work or keeping a job	7 (21.2%)
Travelling	6 (18.2%)
Managing my diabetes	2 (6.1%)
Other	3 (9.1%)
None	3 (9.1%)

Sixty-one percent of respondents with DED, 67% with DME, and 65% without DED were in paid employment (see Table 8 and Appendix 5.1). One in five of those with vision complications reported difficulties, due to DED or DME, with working or keeping a job (21%).

Sixty-five percent of those surveyed did not receive assistance from the government, while small in numbers, respondents who had received such assistance increased in those with DME (57%) and DED (45%) compared to those without DED (27%) (see Appendix Table 4.5 and EXP 5.1).

Seventy-one percent of respondents said they had no trouble paying for food at any time during the past year. This rose from 24% (n=18) in those without DED to 32% (n=12) in those with DED and 56% (n=5) in those with DME (see Appendix Table 4.6 and EXP 5.1).

The majority of respondents (78%) said that they did not feel their access to healthcare was affected by any factors, yet one in ten felt that it was affected by their income (11%) (see Appendix Table 4.7).

Health (59%), family (20%), and money (12%) were the top three 'worries' on the mind of the respondents surveyed (see Appendix Table 4.8).

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

Question	Response	Without DED (n=74)	With DED (n=38)	With DME (n=9)
Are you currently working?	Working for pay	48 (64.9%)	23 (60.5%)	6 (66.7%)
	Working without pay at home (e.g. housework, farming)	3 [4.1%]	2 (5.3%)	1 [11.1%]
	Volunteering	1 (1.4%)	0 (0.0%)	0 (0.0%)
	Retired	4 (5.4%)	9 (23.7%)	1 (11.1%)
	Student	6 (8.1%)	2 (5.3%)	0 (0.0%)
	Not working	12 (16.2%)	2 (5.3%)	1 (11.1%)
Question	Response	Without DED (n=73)	With DED (n=38)	With DME (n=7)
Do you receive assistance from the government?	Income assistance	4 [2.9%]	6 [10.3%]	2 (5.6%)
	Medical assistance	3 (2.1%)	0 (0.0%)	3 (8.3%)
	Food assistance	2 (1.4%)	0 (0.0%)	0 (0.0%)
	Housing assistance	3 (2.1%)	4 (6.9%)	0 (0.0%)
	Pension assistance	4 (2.9%)	3 (5.2%)	4 (11.1%)
Question	Response	Without DED (n=74)	With DED (n=37)	With DME (n=9)
Did you have trouble paying for food at any time during the past year?	Yes	18 (24.3%)	12 (32.4%)	5 (55.6%)
	No	56 (75.7%)	25 (67.6%)	4 (44.4%)

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.

Forty-four percent of people with DME and 35% of those with DED reported self-rated health as poor compared with 32% of people without DED (see Table 9).

Compared with 18% of those without DED, 78% of people with DME and 37% of people with DED experienced limitations to their daily activities as a result of poor health. Where health impacted daily activities, the primary limitations were: diabetes, vision problems and back or neck problems. People living with DED and DME had a higher proportion of some limitations particularly hypertension (see Appendix EXP 2).

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	50 (67.6%)	22 (64.7%)	5 (55.6%)
Self-rated health: Poor	24 (32.4%)	12 (35.3%)	4 (44.4%)
Physically unhealthy days	18 (29.5%)	9 (32.1%)	2 (25.0%)
Mentally unhealthy days	26 (42.6%)	9 (32.1%)	1 (20.0%)
Unhealthy days	34 (58.6%)	15 (53.6%)	2 (40.0%)
Activity limitation days	16 (36.4%)	7 (36.8%)	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]: 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.

# **Brazil DR Barometer Findings:**Health Care Professionals

#### **Key Demographic Characteristics**

There were 124 health care professionals who answered at least one of the survey questions in Brazil. Of these, six were primary care providers (4.8%), 25 were diabetes specialist providers (20%) and 78 were ophthalmologists (63%). The remaining respondents were optometrists, nurses, health educators or other types of 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, as a group, had been practicing for an average of 15 years (see Appendix PT 1.5).

All were well educated (82% with graduate or advanced degree), 38% were female and 62% male, and varied in age with 37% between 40 - 49 years (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 Provider	Ophthalmologist
All respondents		124 (100.0%)	6 (4.8%)	25 (20.2%)	78 (62.9%)
Age group	18 - 29 yrs.	2 (2.6%)	0 (0.0%)	1 (7.7%)	0 (0.0%)
	30 - 39 yrs.	26 (34.2%)	2 (50.0%)	2 (15.4%)	22 (40.0%)
	40 - 49 yrs.	28 (36.8%)	1 (25.0%)	5 (38.5%)	20 (36.4%)
	50 - 59 yrs.	12 (15.8%)	0 (0.0%)	4 (30.8%)	8 (14.5%)
	60 - 69 yrs.	6 (7.9%)	0 (0.0%)	0 (0.0%)	5 (9.1%)
	70 - 79 yrs.	2 (2.6%)	1 (25.0%)	1 (7.7%)	0 (0.0%)
Gender	Female	29 (38.2%)	2 (50.0%)	5 (38.5%)	20 (36.4%)
	Male	47 (61.8%)	2 (50.0%)	8 (61.5%)	35 (63.6%)
Education	College/University	14 (18.4%)	1 (25.0%)	2 (15.4%)	10 (18.2%)
	Graduate or advanced degree (e.g. PhD, MD, etc.)	62 [81.6%]	3 (75.0%)	11 (84.6%)	45 (81.8%)

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

Fifty-five percent of all health care professionals have their main practice setting at a clinic and for ophthalmologists alone it was an eye clinic (82%), a hospital (13%), and a diabetes clinic (2.6%). Ninety-seven percent of health care professionals worked in an urban setting (see Appendix PT 2.1 and 2.2).

Most health care professionals worked in the private sector (58%) and ophthalmologists worked mainly in the private (64%), combined or mixed (23%) and the government (10%) sector (see Appendix PT 2.3).

The health care professionals stated that 54% of patients pay through insurance for services, 47% of patients pay out-of-pocket (full fees) for services and 32% of patients' insurance partly pays. The situation was similar for ophthalmologists: 67% of patients pay through insurance for services, 49% of patients pay out-of-pocket, and 41% of patients' insurance partly pays (see Appendix PT 2.7).

Health care professionals reported on average of seeing 91 patients per week of which an estimated 36% of these patients had diabetes. Ophthalmologists saw an average of 104 patients per week and 29% of their patient population had diabetes (see Appendix PT 2.6).

For all health care professionals, the average waiting time for an appointment was either more than one week but less than one month (50%), less than one week (16%), or between one and two months (14%).

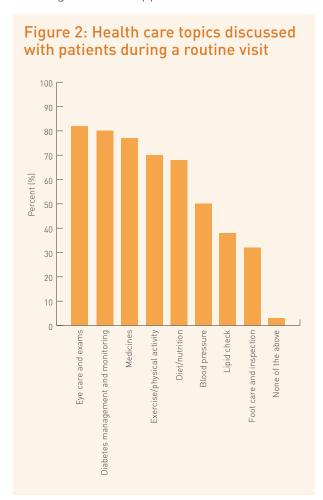
The average wait time for an appointment with an ophthalmologist was more than one week but less than one month in 54% of practices. In a further 16% of practices, the average wait time was less than one week (see Table 11 and Appendix PT 2.5).

Table 11: Average wait times to schedule an appointment

Wait Time Intervals	All Respondents (n=103)	Ophthalmologist (n=69)
Less than 1 week	16 (15.5%)	11 (15.9%)
More than 1 week but less than 1 month	51 (49.5%)	37 (53.6%)
More than 1 month but less than 2 months	14 (13.6%)	9 (13.0%)
More than 2 months but less than 3 months	7 (6.8%)	4 (5.8%)
More than 3 months but less than 6 months	11 (10.7%)	6 (8.7%)
Six or more months	1 (1.0%)	1 (1.4%)
Other	1 (1.0%)	0 (0.0%)
Don't know/Not sure	2 (1.9%)	1 (1.4%)

#### **Patient Education Information**

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



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

Almost half of all providers (48%) did not have written information about diabetes and potential eye complications available for their patients. Over a quarter of all providers (27%) reported that they had sufficient information about eye complications, 14% had information on diabetes, but that which was on eye complications was insufficient, and 5.8% reported that information on eye complications was not included in the available information.

More than half of ophthalmologists (51%) did not have written information available for their patients. Some ophthalmologists (30%) had written information about diabetes and potential eye complications, while 12% had information on diabetes, but that which is on eye complications was insufficient (see Table 12 and Appendix PT 2.11).



#### **Guidelines and Protocols**

Only twenty-eight percent of all providers had written protocols for the management of diabetes available which were used by staff and 57% of all providers had no such protocols (see Appendix PT 2.12).

With respect to the management of diabetes-related vision issues, over half of all providers (54%) did not have written protocols available. Thirty-five percent of health care professionals had written protocols available which were used by staff and 9.5% had protocols available but not used by staff.

For ophthalmologists, 38% had written protocols available which were used by staff. Similar to all providers, 50% of ophthalmologists did not have access to protocols on diabetes-related vision issues (see Table 12 and Appendix PT 2.13).

Table 12: Availability and use of information and protocols

Question	Response	All Respondents (n=86)	Ophthalmologist (n=61)
Is there written information about diabetes available for patients in your main practice?	Yes, and information on eye complications is sufficient	23 (26.7%)	18 (29.5%)
	Yes, but information on eye complications is not sufficient	12 (14.0%)	7 (11.5%)
	Yes, but no information on eye complications is included	5 (5.8%)	1 (1.6%)
	No written information is available for patients	41 (47.7%)	31 (50.8%)
	Don't know/Not sure	5 (5.8%)	4 (6.6%)
Question	Response	All Respondents (n=84)	Ophthalmologist (n=60)
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	29 (34.5%)	23 (38.3%)
	Yes, available but not used by staff	8 (9.5%)	5 (8.3%)
	Not available	45 (53.6%)	30 (50.0%)
	Don't know/Not sure	2 (2.4%)	2 (3.3%)

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

### Screening Protocols and Barriers in the Care Pathway

Recommendations for the timing of the initial eye exam for persons with diabetes varied depending upon the type of diabetes as reported by all providers.

Most providers, for patients with type 1 (55%) or type 2 (82%) diabetes, reported that the initial eye exam should occur at time of the diagnosis of diabetes (see Appendix PT 2.14).

Overall, 84% of health care professionals, including 86% of ophthalmologists, reported that follow-up eye examinations should be conducted every year. Most providers (79%), including 97% of the ophthalmologists, screen patients for DR (see Appendix PT 2.15 and 2.16).

For all health care professionals, 65% reported to send appointment reminders and 32% do not. Ninety-one percent of the providers, including 96% of ophthalmologists, shared information to optimise patient care management (see Appendix PT 2.19 and 2.20).

The most common patient characteristics influencing the referral process for eye complications were: diabetes duration (89%), the presence of comorbidities such as hypertension (76%), high glucose levels (76%), a patient's age (50%), and a patient's ability to adhere to recommendations (15%) (see Appendix PT 2.17).

As reported by all health care professionals, the major barriers to optimising eye health faced by patients with diabetes were: the cost of care (64%), a general lack of knowledge or awareness (55%), and the limited access to diabetes specialists (34%). 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

Response	All Respondents (n=74)	Ophthalmologists (n=54)
Cost of care	47 (63.5%)	40 (74.1%)
Lack of knowledge and/or awareness	41 (55.4%)	35 (64.8%)
Limited access to diabetes specialists	25 (33.8%)	22 (40.7%)
Patients feel eye complications are unlikely	25 (33.8%)	19 (35.2%)
Patients fear of treatment/results	19 (25.7%)	17 (31.5%)
Referral process	24 (32.4%)	16 (29.6%)
Patients feel eye exams are not important	21 (28.4%)	16 (29.6%)
Proximity to care	16 (21.6%)	14 (25.9%)
Limited access to eye specialists	23 (31.1%)	14 (25.9%)
Long wait time for appointment	22 (29.7%)	13 (24.1%)
Recommended treatments are not available	13 (17.6%)	9 (16.7%)
Patients have competing responsibilities and priorities	12 [16.2%]	9 (16.7%)
Long wait time on the day of visit	6 (8.1%)	4 (7.4%)
Patients feel they are a burden on family/friends	3 (4.1%)	3 (5.6%)
Clinic too small or lack necessary equipment/staff	7 (9.5%)	2 (3.7%)
Other	3 (4.1%)	3 (5.6%)

# **Brazil DR Barometer Findings:**Ophthalmologists

#### Screening

There were fifty ophthalmologists who answered at least one of the supplementary questions (see Appendix PT 4.1 to PT 4.14).

The ophthalmologists reported that an average of 24% of their patients had DR and 16% DME (see Appendix PT 4.1 and PT 4.2).

The most common waiting time for a screening appointment for DED was more than one week but less than one month (47%) while 24% stated less than one week. Fifty-eight percent of ophthalmologists reported that there was no wait from the time of screening to diagnosis, 29% reported a wait time of less than 1 week (see Appendix PT 4.3 and PT 4.4).

#### **Treatment and Challenges**

Eighty-nine percent of ophthalmologists personally administer treatment for diabetic retinopathy (See Appendix PT 4.6).

The most common factors influencing how ophthalmologists treat patients with DR or DME were: high glucose levels (53%), diabetes duration (44%) and the presence of comorbidities such as hypertension (33%) (see Appendix PT 4.7).

The most common outreach venues for screening for DED were reported to be at mobile screening centres (30%), at vision centres (30%), health fairs for all (19%), other (13%), health fairs for people with diabetes (8.5%) however, it is important to note that 25% did not conduct any outreach services (see Appendix PT 4.13).

Ninety-six percent ophthalmologists reported that they screen patients for DR based on fundoscopy through dilated pupils. Additionally 60% use fluorescein angiography, 59% use optical coherence tomography and 53% use retinal photo. Ninety-three percent of ophthalmologists reported that they treat DR and DME based on both visual and anatomical outcomes (see Appendix PT 4.8 and PT 4.9).

Seventy-nine percent of ophthalmologists said that most patients present when visual problems have already occurred, 13% (n=7) said that patients present in time for screening and 7.5% (n=4) said that patients present too late for effective treatment (see Appendix PT 4.10).

Ninety-four percent of the ophthalmologists had received specific training in the treatment and diagnosis of DR and / or clinically significant DME, of which 48% had received training within the past year, 21% more than one year ago but less than five years, and 31% received training five or more years ago. Seventy-three percent 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 reported that the greatest challenges for improving patient outcomes in DED were late diagnosis (76%), limited access to patient education on DR and DME (68%), and reimbursement or restrictions on approved therapy (56%) (see Table 14 and Appendix 4.14).



Table 14: Challenges for improving outcomes in DED

Question	Response	Ophthalmologist (n=50)
What do you perceive to be the	Late diagnosis	38 (76.0%)
greatest challenges for improving patient outcomes in diabetic eye disease?	Limited access to patient education on diabetic retinopathy and diabetic macular edema	34 (68.0%)
	Reimbursement/restrictions on approved therapy	28 (56.0%)
	Government/insurance not able to cover patient costs	26 (52.0%)
	Referral pathways	23 (46.0%)
	Multi-disciplinary team integration is poor	18 (36.0%)
	Ineffective screening services	14 (28.0%)
	No universal guidelines on referral/ screening	12 (24.0%)
	No universal guidelines on how to treat	9 (18.0%)
	No universal guideline on when to treat	5 (10.0%)
	Current available therapies not effective	2 [4.0%]
	Other	2 (4.0%)

## Brazil DR Barometer Summary

In Brazil, 139 adults with diabetes and 124 health care professionals have provided insight about their experiences of living with, managing and treating diabetes, DR and DME.

The results of the DR Barometer Study, Brazil were intended to assess 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.

Brazil is estimated to be the most populous country in Latin America with a population of approximately 209.5 million and also has the highest number of people living with diabetes in the South and Central America region at ~14.3 million accounting for ~48% of people living with diabetes in this region.

It is important to note that Brazil is fifth in the world for diabetes-related health expenditures at 22 billion USD and expected to increase to an estimated 36 billion USD by 2040. Deaths attributed to diabetes in Brazil in 2015 were 130,712, which accounts to over half (~53%) of the diabetes-related deaths experienced in this region.

Although Brazil currently has a relatively young population this is predicted to drastically change in the decades to come despite its increasing population. By 2050, it is projected that those under the age of 15 will only make up 15% of the total population while those over the age of 65 will make up 22% of the total population. This means that in just over thirty years the population for those aged 65 or older will increase by 218%, reaching an all-time high of approximately 54.2 million.

The DR Barometer Study 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. Eighty-two percent of those in the youngest age group (18-39 years) had type 1 diabetes (18% type 2) and in the 40 – 59 age group 33% had type 1 (63% type 2). This is an important, but well-known finding, in the context of Brazil's anticipated demographic shift in ageing population.

Of the adults with diabetes who responded to the survey in Brazil, 27% (n=38) reported to be diagnosed with DED and 6.5% (n=9) had DMF.

People were most often informed about their condition by health professionals such as the doctor, nurse. The nutritionist or dietician, and diabetes or other health organisations also played important roles and were viewed as valuable sources of information. A trend globally which was reflected in the Brazilian study was the increasing use of the internet by almost a third (31%) of respondents.

Many of those surveyed struggled with the management of their diabetic condition with some issues that were beyond their personal control such as the high cost of care, long wait times for an appointment to see their doctor, or specialist, and not having insurance. These factors could play a role in the finding that less than one-quarter of patients were currently enrolled in a diabetes management programme.



There was not only a relatively high awareness of the complications but vision loss was feared two times more than cardiovascular disease or stroke and three times more than the loss of a limb.

While more than half (55%) of those surveyed had no complications there was still many who reported having neuropathy, kidney disease and vision loss. There was also an increase in the frequency of people with DED and DME experiencing some complications compared with people without DED. The frequency of cardiovascular disease, stroke or neuropathy had a marked increase in those with DED and DME compared with those without DED.

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 the high costs of exams, long wait times to schedule an appointment, and the complicated or delayed referral process.

The relationship between the patient and the health care professional is critical to realistic and optimal patient outcomes. Indeed, health education and information were reported by patients as the one of the most important tools to improve the management of one's diabetes yet one in four respondents did not receive any information on eye complications from traditional sources, such as their doctor or nurse.

Likewise, over half of health care professionals reported one of the major barriers to optimising eye health was a lack of knowledge or awareness and yet more than two-thirds (68%) of these providers either did not have information on diabetes-related eye health available for their patients or that which they had was insufficient.

Knowledge and guidance was not only an issue for patients, as almost one in two providers said that they did not have any written protocols or guidelines available in the management of either diabetes or diabetes-related vision issues.

Seventy-one percent of people with DED or DME said that their vision was slightly or significantly affected which in turn impacted their health, lifestyle and life choices. One in five of those with vision complications reported difficulties with working or keeping a job, and sadly, a third of people had difficulty interacting with family and friends.

People with DED and DME also experienced more unhealthy days when compared to those without DED. Almost a third (32%) of people without DED reported self-rated health as poor compared with 44% of those with DME. Furthermore, 78% of those with DME experienced days where their activities were limited due to poor physical or mental health compared with only 18% of those without DED.

A proactive treatment approach to prevent further vision loss was preferred by all those with DME rather than reactive treatment once further vision loss had occurred. However, for some people (11%) access to healthcare was affected by their income. Health, family, and money were the top three 'worries' on the mind of the respondents surveyed.

Supporting this, ophthalmologists reported the cost of care as the single major barrier in optimising eye health, and one in four (28%) patients cited the cost of the eye exam was too expensive.

For patients with both type 1 and type 2 diabetes, 55% and 82% 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. Yet, almost a third (32%) of providers did not send reminders to their patient to schedule an appointment.

The top patient characteristics influencing the referral process for eye complications across providers and ophthalmologists were diabetes duration, presence of comorbidities such as hypertension, high glucose levels, and a patient's age. Three in four ophthalmologists said that the majority of their patients present when visual problems have already occurred, and sadly, some present too late for effective treatment. Late diagnosis, access to patient education, and reimbursement restrictions on approved therapies were viewed by ophthalmologists as the greatest challenges for improving patient outcomes in DED in Brazil.

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 action in Brazil.



## 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%20 Nutrition%20and%20Population%20 Statistics:%20Population%20estimates %20and%20projections

The IFA, IDF and IAPB would like to acknowledge and thank the many organisations and health care professionals from Brazil 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 Brazil

#### **APPENDIX 1: National Results**

#### Table 1.1

Survey Information	Number of Respondents (%)
All valid respondents [1]	182 (100.0%)
Respondents aged 18 or over	170 (93.4%)
Respondents with diabetes	141 (77.5%)

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

#### Table 1.2

Survey Information	Number of Respondents (%)
All valid respondents	182 (100.0%)
Included in Diabetic Analysis Set	139 (76.4%)
Excluded from Diabetic Analysis Set	43 (23.6%)
Reasons for exclusion from diabetic analysis set	•
Under 18 years of age	12
Not diagnosed with diabetes	20
Missing information on diabetes diagnosis	9
Gestational diabetes only	2

#### Table 1.3

Survey Information	Number of Respondents (%)
Diabetic Analysis Set	139 (100.0%)
World Bank Income Group: Upper-middle income	139 (100.0%)
Persons with diabetic eye disease (DED)	38 (27.3%)
Persons with diabetic macular edema (DME)	9 (6.5%)
Persons with Type I diabetes	79 (56.8%)
Persons with Type II diabetes	56 (40.3%)
Persons not seeing health care professional for diabetes	3 (2.2%)
Persons seeing health care professional for diabetes	135 (97.1%)
Persons with eye disease & not received treatment	3 (2.2%)

Survey Information	Number of Respondents (%)
Persons with eye disease & received treatment	41 (29.5%)

#### Table 2.1

Question	Response	Number of Respondents (%)
With which type of diabetes have you been diagnosed?	Type I	79 (56.8)
	Type II	56 (40.3)
	Don't know/Not sure	4 (2.9)
	Total Valid Response	139 (100.0)

#### Table 2.2

Question	Response	Number of Respondents (%)
When was your diabetes diagnosed?	Within the last year	8 (5.8)
	1 - 5 years ago	33 (23.9)
	6 - 10 years ago	28 (20.3)
	11 - 15 years ago	19 (13.8)
	16 - 20 years ago	23 (16.7)
	21 years ago or longer	26 (18.8)
	Don't know/Not sure	1 (0.7)
	Total Valid Response	138 (100.0)
	Total missing	1

#### **Table 2.3.1**

Question	Response	Number of Respondents (%)
Do you see a health care professional for your diabetes?	Yes	135 (97.8)
	No	3 (2.2)
	Total Valid Response	138 (100.0)
	Total missing	1
What kind of health care professional?	General/Family Doctor	36 (27.3)
	Diabetes Specialist	92 (69.7)



Question	Response	Number of Respondents (%)
	Other	4 (3.0)
	Total Valid Response	132 (100.0)
	Total missing	7

#### **Table 2.3.2**

Type of health care professional	Times per year seen for diabetes	Value
General/Family Doctor	Total valid numeric response (n)	32
	Mean	2.5
	SD	1.7
	Median	2.0
	Min	1
	Max	10
	Don't know/Not sure	1
	Total missing	3
Diabetes Specialist	Total valid numeric response (n)	77
	Mean	3.5
	SD	1.7
	Median	3.0
	Min	1
	Max	12
	Don't know/Not sure	4
	Total missing	11
Other	Total valid numeric response (n)	4
	Mean	3.0
	SD	0.8
	Median	3.0
	Min	2
	Max	4

#### Table 2.4

Question	Response	Number of
		Respondents (%)

Question	Response	Number of Respondents (%)
How have you received information about diabetes?	Doctor or nurse	123 (91.1%)
	Health educator	20 (14.8%)
	Nutritionist or dietitian	39 (28.9%)
	Diabetes organization or other health organization	32 (23.7%)
	Family/Friends/Neighbors	23 (17.0%)
	TV/Radio/Newspaper/Magazines	20 (14.8%)
	Internet	42 (31.1%)
	Social media (e.g. Facebook, Twitter, blogs)	23 (17.0%)
	Pharmacist	4 (3.0%)
	None of the above	5 (3.7%)
	Total Valid Response	135 (100.0%)
	Total missing	4

#### Table 2.5

Question	Response	Number of Respondents (%)
How do you manage your diabetes?	Diet	91 (67.9%)
	Oral medicine	53 (39.6%)
	Exercise	61 (45.5%)
	Insulin	95 (70.9%)
	Natural/Herbal medicine	2 (1.5%)
	None of the above	2 (1.5%)
	Total Valid Response	134 (100.0%)
	Total missing	5

Table 2.6

Question	Response	Number of Respondents (%)
Are you currently enrolled in a diabetes patient management support programme?	Yes	32 (23.7)
	No	103 (76.3)
	Total Valid Response	135 (100.0)



Question	Response	Number of Respondents (%)
	Total missing	4
Who sponsors the programme?	Hospital support program	3 (9.7)
	Clinic support program	2 (6.5)
	Pharmaceutical support program	8 (25.8)
	Patient organization support program	12 (38.7)
	Don't know/Not sure	6 (19.4)
	Total Valid Response	31 (100.0)
	Total missing	108
Does the programme include education on the importance of screening for diabetic eye complications?	Yes	25 (78.1)
	No	7 (21.9)
	Total Valid Response	32 (100.0)
	Total missing	107

#### Table 2.7

Test	Response	Number of Respondents (%)
Have you ever had the following tests in a doctors office of clinic? And if yes, how long ago?		
Blood glucose test	Yes	122 (92.4%)
	Less than 6 months	95 (72.0%)
	6 - 12 months	16 (12.1%)
	Greater than 12 months	8 (6.1%)
	Total valid response	119 (90.2%)
	Total missing	20
	No	9 (6.8%)
	Don't know/Not sure	1 (0.8%)
	Total valid response	132 (100.0%)

Test	Response	Number of Respondents (%)
	Total missing	7
Urine check	Yes	111 (86.0%)
	Less than 6 months	60 (46.5%)
	6 - 12 months	31 (24.0%)
	Greater than 12 months	15 (11.6%)
	Total valid response	106 (82.2%)
	Total missing	33
	No	16 (12.4%)
	Don't know/Not sure	2 (1.6%)
	Total valid response	129 (100.0%)
	Total missing	10
Weight check	Yes	120 (93.0%)
	Less than 6 months	92 (71.3%)
	6 - 12 months	17 (13.2%)
	Greater than 12 months	7 (5.4%)
	Total valid response	116 (89.9%)
	Total missing	23
	No	6 (4.7%)
	Don't know/Not sure	3 (2.3%)
	Total valid response	129 (100.0%)
	Total missing	10
Blood pressure check	Yes	116 (88.5%)
	Less than 6 months	85 (64.9%)
	6 - 12 months	23 (17.6%)
	Greater than 12 months	5 (3.8%)



Test	Response	Number of Respondents (%)
	Total valid response	113 (86.3%)
	Total missing	26
	No	10 (7.6%)
	Don't know/Not sure	5 (3.8%)
	Total valid response	131 (100.0%)
	Total missing	8
Foot check	Yes	73 (59.3%)
	Less than 6 months	37 (30.1%)
	6 - 12 months	19 (15.4%)
	Greater than 12 months	15 (12.2%)
	Total valid response	71 (57.7%)
	Total missing	68
	No	47 (38.2%)
	Don't know/Not sure	3 (2.4%)
	Total valid response	123 (100.0%)
	Total missing	16
Eye check	Yes	115 (87.1%)
	Less than 6 months	56 (42.4%)
	6 - 12 months	36 (27.3%)
	Greater than 12 months	21 (15.9%)
	Total valid response	113 (85.6%)
	Total missing	26
	No	16 (12.1%)
	Don't know/Not sure	1 (0.8%)
	Total valid	132 (100.0%)

Test	Response	Number of Respondents (%)
	response	
	Total missing	7

Question	Response	Number of Respondents (%)
How well do you think your diabetes is controlled?	Very well	17 (12.9%)
	Well	62 (47.0%)
	Not very well	42 (31.8%)
	Not well at all	9 (6.8%)
	Don't know/Not sure	2 (1.5%)
	Total Valid Response	132 (100.0%)
	Total missing	7

Question	Response	Number of Respondents (%)
What are the main challenges you face in controlling your diabetes?	High cost of care	43 (33.1%)
	No insurance	14 (10.8%)
	Travel to my regular doctor or specialist is difficult	9 (6.9%)
	Long wait time for an appointment to see my doctor or specialist	22 (16.9%)
	Health services needed are not available	10 (7.7%)
	Don't know enough about diabetes	10 (7.7%)
	Too hard to eat the right things	77 (59.2%)
	Too many other things to do	23 (17.7%)
	Stigma or discrimination because of diabetes	7 (5.4%)
	Don't want to think about having diabetes	5 (3.8%)



Question	Response	Number of Respondents (%)
	Other	20 (15.4%)
	Total Valid Response	130 (100.0%)
	Total missing	9

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	85 (65.9%)
	Support groups	12 (9.3%)
	Support from family or friends	63 (48.8%)
	Health education and information	57 (44.2%)
	Mobile services (services that travel to or near your home)	12 (9.3%)
	Coordination of healthcare and services by a professional	19 (14.7%)
	Emergency helpline	7 (5.4%)
	Other	14 (10.9%)
	None	9 (7.0%)
	Total Valid Response	129 (100.0%)
	Total missing	10

Question	Response	Number of Respondents (%)
What complications (or problems), to your knowledge, arise from diabetes?	Amputation	111 (85.4%)
	Foot ulcers	79 (60.8%)
	Increased risk of broken bones or fractures	29 (22.3%)
	Loss of feeling in hands or toes (neuropathy)	92 (70.8%)
	Vision loss	120 (92.3%)
	Irritable bowel disease	22 (16.9%)
	Kidney disease	93 (71.5%)

Question	Response	Number of Respondents (%)
	Cardiovascular disease/Stroke	93 (71.5%)
	Other	11 (8.5%)
	Don't know/Not sure	4 (3.1%)
	None	1 (0.8%)
	Total Valid Response	130 (100.0%)
	Total missing	9

Question	Response	Number of Respondents (%)
Which complication of diabetes are you most concerned about?	Amputation	19 (14.8)
	Vision loss	61 (47.7)
	Kidney disease	19 (14.8)
	Cardiovascular disease/Stroke	26 (20.3)
	Don't know/Not sure	2 (1.6)
	None	1 (0.8)
	Total Valid Response	128 (100.0)
	Total missing	11

Question	Response	Number of Respondents (%)
Which of the following complications of diabetes do you have?	Amputation	1 (0.8%)
	Foot ulcers	2 (1.6%)
	Loss of feeling in hands or toes (neuropathy)	8 (6.6%)
	Vision loss	31 (25.4%)
	Irritable bowel disease	8 (6.6%)
	Kidney disease	6 (4.9%)
	Cardiovascular disease/Stroke	4 (3.3%)
	Other	4 (3.3%)



Question	Response	Number of Respondents (%)
	Don't know/Not sure	5 (4.1%)
	None	67 (54.9%)
	Total Valid Response	122 (100.0%)
	Total missing	17

Question	Response	Number of Respondents (%)
How often do you discuss the possibility of eye complications with your health care professional?	Every visit	45 (36.6%)
	Multiple times per year	17 (13.8%)
	Once per year	25 (20.3%)
	Only when symptoms arise	21 (17.1%)
	Never	13 (10.6%)
	Don't know/Not sure	2 (1.6%)
	Total Valid Response	123 (100.0%)
	Total missing	16

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	14 (11.6%)
	I do what I can to prevent vision problems (e.g. get routine screenings, visit specialists)	97 (80.2%)
	I do not make any special effort to prevent vision problems	15 (12.4%)
	Total Valid Response	121 (100.0%)
	Total missing	18

**Table 2.16** 

Question	Response	Number of Respondents (%)
What type of health insurance do you have?	Public	24 (19.2)
	Public - Private	39 (31.2)
	Private	59 (47.2)
	None	3 (2.4)
	Total Valid Response	125 (100.0)
	Total missing	14

**Table 2.17** 

Response	Number of
	Respondents (%)
Care is free	22 (19.3)
Insurance pays total cost	54 (47.4)
Insurance and out-of-	23 (20.2)
pocket/cash (e.g. co-pays)	
Out-of-pocket only (pay	13 (11.4)
cash for all care)	
Do not use service	2 (1.8)
Total Valid Response	114 (100.0)
Total missing	25
Care is free	16 (13.2)
Insurance pays total cost	54 (44.6)
Insurance and out-of-	24 (19.8)
pocket/cash (e.g. co-pays)	
Out-of-pocket only (pay	26 (21.5)
cash for all care)	
Do not use service	1 (0.8)
Total Valid Response	121 (100.0)
Total missing	18
Care is free	48 (40.3)
Insurance pays total cost	6 (5.0)
Insurance and out-of-	5 (4.2)
pocket/cash (e.g. co-pays)	
Out-of-pocket only (pay	46 (38.7)
	Care is free Insurance pays total cost Insurance and out-of- pocket/cash (e.g. co-pays) Out-of-pocket only (pay cash for all care) Do not use service Total Valid Response Total missing Care is free Insurance pays total cost Insurance and out-of- pocket/cash (e.g. co-pays) Out-of-pocket only (pay cash for all care) Do not use service Total Valid Response Total missing Care is free Insurance and out-of- pocket/cash (e.g. co-pays)



Question	Response	Number of Respondents (%)
	cash for all care)	
	Do not use service	14 (11.8)
	Total Valid Response	119 (100.0)
	Total missing	20
Medical supplies (e.g. blood glucose meter/strips)	Care is free	44 (36.7)
	Insurance pays total cost	11 (9.2)
	Insurance and out-of- pocket/cash (e.g. co-pays)	9 (7.5)
	Out-of-pocket only (pay cash for all care)	41 (34.2)
	Do not use service	14 (11.7)
	Don't know/Not Sure	1 (0.8)
	Total Valid Response	120 (100.0)
	Total missing	19
Procedures	Care is free	20 (17.5)
	Insurance pays total cost	49 (43.0)
	Insurance and out-of- pocket/cash (e.g. co-pays)	24 (21.1)
	Out-of-pocket only (pay cash for all care)	16 (14.0)
	Do not use service	2 (1.8)
	Don't know/Not Sure	3 (2.6)
	Total Valid Response	114 (100.0)
	Total missing	25
Tests/screenings	Care is free	19 (16.1)
	Insurance pays total cost	56 (47.5)
	Insurance and out-of- pocket/cash (e.g. co-pays)	26 (22.0)
	Out-of-pocket only (pay cash for all care)	14 (11.9)
	Do not use service	2 (1.7)
	Don't know/Not Sure	1 (0.8)
	Total Valid Response	118 (100.0)
	Total missing	21

Question	Response	Number of Respondents (%)
Health education	Care is free	31 (27.0)
	Insurance pays total cost	7 (6.1)
	Insurance and out-of- pocket/cash (e.g. co-pays)	4 (3.5)
	Out-of-pocket only (pay cash for all care)	9 (7.8)
	Do not use service	57 (49.6)
	Don't know/Not Sure	7 (6.1)
	Total Valid Response	115 (100.0)
	Total missing	24
Counseling	Care is free	22 (19.3)
	Insurance pays total cost	10 (8.8)
	Insurance and out-of- pocket/cash (e.g. co-pays)	6 (5.3)
	Out-of-pocket only (pay cash for all care)	8 (7.0)
	Do not use service	61 (53.5)
	Don't know/Not Sure	7 (6.1)
	Total Valid Response	114 (100.0)
	Total missing	25

Question	Response	Number of Respondents (%)
Are you aware of any government sponsored screening programs for diabetic eye disease (diabetic retinopathy)?	Yes	37 (29.6%)
	No	88 (70.4%)
	Total valid response	125 (100.0%)
	Total missing	14

Question	Response	Number of Respondents (%)
Have you ever had an eye exam for diabetic eye disease?	Yes	110 (87.3%)



Question	Response	Number of Respondents (%)
	No	16 (12.7%)
	Total valid response	126 (100.0%)
	Total missing	13
How long ago was your last eye exam?	Within the last year	78 (71.6%)
	More than 1 year ago but less than 2 years	20 (18.3%)
	More than 2 years ago but less than 3 years	5 (4.6%)
	More than 3 years ago but less than 5 years	4 (3.7%)
	Five or more years ago	1 (0.9%)
	Don't know/Not sure	1 (0.9%)
	Total valid response	109 (100.0%)
	Total missing	30
Who did the last exam?	Eye doctor/Eye clinic	107 (99.1%)
	Other	1 (0.9%)
	Total valid response	108 (100.0%)
	Total missing	31

Question	Response	Number of Respondents (%)
Have you ever had a dilated eye exam, where your eyes are examined after eye drops?	Yes	113 (91.9%)
	No	7 (5.7%)
	Don't know/Not sure	3 (2.4%)
	Total valid response	123 (100.0%)
	Total missing	16

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	113 (91.9%)

Question	Response	Number of Respondents (%)
	Every two years	7 (5.7%)
	Only when symptoms occur	1 (0.8%)
	Don't know/Not sure	2 (1.6%)
	Total valid response	123 (100.0%)
	Total missing	16

Table 3.5

Question	Response	Number of Respondents (%)
For you, what are the biggest barriers to eye exams?	They are expensive	29 (27.6%)
	Eye exams are not available near my home	17 (16.2%)
	Long wait time for appointment	26 (24.8%)
	Long wait time on the day of the visit	13 (12.4%)
	Referral process is complicated or takes too long	20 (19.0%)
	Recommended treatments for eye problems are not available	5 (4.8%)
	Don't know much about my condition	5 (4.8%)
	Fear of treatment/results	8 (7.6%)
	Burden on my family/friends	1 (1.0%)
	Limited access to diabetes specialists	11 (10.5%)
	I'm not likely to have eye complications	4 (3.8%)
	Too many other things to do or worry about	11 (10.5%)
	Clinics are too small or lack necessary equipment/staff	3 (2.9%)
	Other	28 (26.7%)
	Total valid response	105 (100.0%)
	Total missing	34

Table 3.6



Question	Response	Number of Respondents (%)
Have you been diagnosed with diabetic eye disease?	Yes	46 (36.8%)
	No	79 (63.2%)
	Total valid response	125 (100.0%)
	Total missing	14
Has your diabetic eye disease affected your vision?	Yes, slightly	25 (54.3%)
	Yes, significantly	8 (17.4%)
	No	13 (28.3%)
	Total valid response	46 (100.0%)
	Total missing	93
Have vision issues caused you to have difficulty with any of the following?	Traveling	6 (18.2%)
	Household responsibilities, such as cooking or cleaning	11 (33.3%)
	Social interactions with family/friends	11 (33.3%)
	Leisure activities/exercise	12 (36.4%)
	Work or keeping a job	7 (21.2%)
	Managing my diabetes	2 (6.1%)
	Other	3 (9.1%)
	None	3 (9.1%)
	Driving (a car/vehicle)	20 (60.6%)
	Total valid response	33 (100.0%)
	Total missing	106

Question	Response	Number of Respondents (%)
Have you had any treatment for diabetic eye disease?	Yes	41 (89.1%)
	No	3 (6.5%)
	Don't know/Not sure	2 (4.3%)
	Total valid response	46 (100.0%)
	Total missing	93

Question	Response	Number of Respondents (%)
What treatment did you receive?	Laser	28 (70.0%)
	Injection in the eye (Anti- VEGF)	15 (37.5%)
	Surgery	4 (10.0%)
	Other	2 (5.0%)
	Total valid response	40 (100.0%)
	Total missing	99
Did you complete the treatment?	Yes	23 (56.1%)
	No	4 (9.8%)
	Still receiving treatment	13 (31.7%)
	Don't know/Not sure	1 (2.4%)
	Total valid response	41 (100.0%)
	Total missing	98
Do you feel that the treatment worked?	Yes, and vision improved	24 (64.9%)
	Yes, but vision stayed the same	5 (13.5%)
	Still waiting to know	7 (18.9%)
	Don't know/Not sure	1 (2.7%)
	Total valid response	37 (100.0%)
	Total missing	102
What is/are the reason(s) that you did not complete the treatment?	Treatment was too expensive	1 (25.0%)
	Eye doctor was located too far away	1 (25.0%)
	Appointment times were not convenient	1 (25.0%)
	I was fearful (scared) of treatment	2 (50.0%)
	Total valid response	4 (100.0%)
	Total missing	135
What are the reason(s) that you have not had treatment for diabetic eye disease?	My doctor did not recommend any treatment	2 (100.0%)
	Treatment is not accessible	1 (50.0%)
	Still waiting for treatment	1 (50.0%)
	Too expensive	1 (50.0%)



Question	Response	Number of Respondents (%)
	Total valid response	2 (100.0%)
	Total missing	137

Question	Response	Number of Respondents (%)
Have you been diagnosed with diabetic macular edema?	Yes	9 (7.5%)
	No	102 (85.0%)
	Don't know/Not sure	9 (7.5%)
	Total valid response	120 (100.0%)
	Total missing	19
If Yes, which of the following would you prefer	Treatment to prevent further vision loss	9 (100.0%)
	Total valid response	9 (100.0%)
	Total missing	130

Question	Response	Number of Respondents (%)
Have you received information about diabetic retinopathy or diabetic macular edema from any of the following sources?	Doctor/Nurse	68 (60.2%)
	Health educator	7 (6.2%)
	Diabetes organization or other health organization	10 (8.8%)
	Family/Friends/Neighbors	8 (7.1%)
	TV/Radio/Newspaper/Magazines	7 (6.2%)
	Internet	26 (23.0%)
	None of the above	29 (25.7%)
	Total valid response	113 (100.0%)
	Total missing	26

Table 4.1

Question	Response	Number of Respondents (%)
What is your gender?	Female	84 (69.4)
	Male	37 (30.6)
	Total Valid Response	121 (100.0)
	Total missing	18
Please indicate your age	18 - 29	42 (30.2)
	30 - 39	30 (21.6)
	40 - 49	18 (12.9)
	50 - 59	25 (18.0)
	60 - 69	14 (10.1)
	70 - 79	7 (5.0)
	80 - 89	2 (1.4)
	90 years and above	1 (0.7)
	Total Valid Response	139 (100.0)

#### Table 4.2

Question	Response	Number of Respondents (%)
Where do you live?	Urban setting	116 (96.7)
	Non-urban setting	4 (3.3)
	Total Valid Response	120 (100.0)
	Total missing	19

### Table 4.3

Question	Response	Number of Respondents (%)
What is the highest level of education you completed?	Did not complete primary school	3 (2.5)
	Primary school	4 (3.3)
	Secondary school	33 (27.3)
	College/University	41 (33.9)
	Graduate or post-graduate	40 (33.1)
	Total valid response	121 (100.0)
	Total missing	18

Table 4.4



Question	Response	Number of Respondents (%)
Are you currently working?	Working for pay	77 (63.6)
	Working without pay at home (e.g. housework, farming)	6 (5.0)
	Volunteering	1 (0.8)
	Retired	14 (11.6)
	Student	8 (6.6)
	Not working	15 (12.4)
	Total Valid Response	121 (100.0)
	Total missing	18

### Table 4.5

Question	Response	Number of Respondents (%)
Do you receive assistance from the government?	Income assistance	5 (4.2%)
	Medical assistance	34 (28.8%)
	Food assistance	1 (0.8%)
	Pension assistance	6 (5.1%)
	None of the above	77 (65.3%)
	Total valid response	118 (100.0%)
	Total missing	21

### Table 4.6

Question	Response	Number of Respondents (%)
Did you have trouble paying for food at anytime during the past year?	Yes	35 (29.2)
	No	85 (70.8)
	Total Valid Response	120 (100.0)
	Total missing	19

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	2 (1.8)
	Education	2 (1.8)
	Ethnicity	1 (0.9)
	Income	12 (11.0)
	Place where you live	9 (8.3)
	Race	2 (1.8)
	Sexual orientation	1 (0.9)
	Tribal affiliation	1 (0.9)
	None of the above	85 (78.0)
	Total valid response	109 (100.0)
	Total missing	30

### Table 4.8

Question	Response	Number of Respondents (%)
Which of the following do you worry about most?	Food	6 (5.1)
	Housing	5 (4.2)
	Money	14 (11.9)
	Health	69 (58.5)
	Family	23 (19.5)
	None of the above	1 (0.8)
	Total Valid Response	118 (100.0)
	Total missing	21

Table 5.1

Question	Response	Number of Respondents (%)
In general, would you say your health is:	Excellent	5 (4.3%)
	Very good	21 (17.9%)



Question	Response	Number of Respondents (%)
	Good	51 (43.6%)
	Total good health	77 (65.8%)
	Fair	34 (29.1%)
	Poor	6 (5.1%)
	Fair or poor health	40 (34.2%)
	Total valid response	117 (100.0%)
	Total missing	22

## Table 5.2

Question	Response	Number of Respondents (%)
How many days during last 30 days was your physical health not good	Any unhealthy days	29 (29.9%)
	1-5 unhealthy days	11 (11.3%)
	6-10 unhealthy days	8 (8.2%)
	11-20 unhealthy days	4 (4.1%)
	21-30 unhealthy days	6 (6.2%)
	No unhealthy days	68 (70.1%)
	Total valid response	97 (100.0%)
	Total missing	42

## **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	36 (38.3%)
	1-5 unhealthy days	14 (14.9%)
	6-10 unhealthy days	6 (6.4%)
	11-20 unhealthy days	6 (6.4%)

Question	Response	Number of Respondents (%)
	21-30 unhealthy days	10 (10.6%)
	No unhealthy days	58 (61.7%)
	Total valid response	94 (100.0%)
	Total missing	45

### **Table 5.3.2**

Question	Response	Number of Respondents (%)
Unhealthy days (physically or mentally unhealthy, max 30)	Any unhealthy days	51 (56.0%)
	1-5 unhealthy days	18 (19.8%)
	6-10 unhealthy days	8 (8.8%)
	11-20 unhealthy days	8 (8.8%)
	21-30 unhealthy days	17 (18.7%)
	No unhealthy days	40 (44.0%)
	Total valid response	91 (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	23 (34.8%)
	1-5 unhealthy days	10 (15.2%)
	6-10 unhealthy days	6 (9.1%)
	11-20 unhealthy days	3 (4.5%)
	21-30 unhealthy days	4 (6.1%)



Question	Response	Number of Respondents (%)
	No unhealthy days	43 (65.2%)
	Total valid response	66 (100.0%)
	Total missing	73

#### 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	34 (29.1%)
	No	83 (70.9%)
	Total valid response	117 (100.0%)
	Total missing	22
Which impairment or health problem, if any, limits your activities?		
a) Arthritis/rheumatism	Yes	10 (40.0%)
	No	13 (52.0%)
	Don't know/Not sure	2 (8.0%)
	Total valid response	25 (100.0%)
	Total missing	114
b) Back or neck problem	Yes	11 (40.7%)
	No	15 (55.6%)
	Don't know/Not sure	1 (3.7%)
	Total valid response	27 (100.0%)
	Total missing	112
c) Fractures, bone/joint injury	Yes	7 (30.4%)
	No	16 (69.6%)
	Total valid response	23 (100.0%)
	Total missing	116

Question	Response	Number of Respondents (%)
d) Walking problem	Yes	10 (40.0%)
	No	15 (60.0%)
	Total valid response	25 (100.0%)
	Total missing	114
e) Lung/breathing problem	Yes	4 (16.0%)
	No	21 (84.0%)
	Total valid response	25 (100.0%)
	Total missing	114
f) Hearing problem	Yes	4 (16.7%)
	No	20 (83.3%)
	Total valid response	24 (100.0%)
	Total missing	115
g) Eye/vision problem	Yes	19 (63.3%)
	No	10 (33.3%)
	Don't know/Not sure	1 (3.3%)
	Total valid response	30 (100.0%)
	Total missing	109
h) Heart problem	Yes	4 (15.4%)
	No	22 (84.6%)
	Total valid response	26 (100.0%)
	Total missing	113
i) Stroke problem	No	25 (100.0%)
	Total valid response	25 (100.0%)
	Total missing	114
j) Hypertension/high blood pressure	Yes	8 (30.8%)
	No	17 (65.4%)
	Don't know/Not sure	1 (3.8%)



Question	Response	Number of Respondents (%)
	Total valid response	26 (100.0%)
	Total missing	113
k) Diabetes	Yes	23 (74.2%)
	No	6 (19.4%)
	Don't know/Not sure	2 (6.5%)
	Total valid response	31 (100.0%)
	Total missing	108
I) Cancer	Yes	1 (4.3%)
	No	22 (95.7%)
	Total valid response	23 (100.0%)
	Total missing	116
m) Mental or emotional health	Yes	7 (26.9%)
	No	16 (61.5%)
	Don't know/Not sure	3 (11.5%)
	Total valid response	26 (100.0%)
	Total missing	113

### PT 1.2

Analysis Sets	Number of Respondents (%)
All valid respondents	124 (100.0%)
Included in Provider Analysis Set (PAS)	124 (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	124
Included in the Eye Care Professional Set (Eye Specialist)	79 (63.7%)
Excluded in the Eye Care Professional Set (Eye Specialist)	45 (36.3%)

Analysis Sets	Number of Respondents (%)
Reasons for exclusion from Eye Care Professional Set:	
Missing required speciality	45
No valid (non-missing) response for the supplemental eye questionnaire	0

#### PT 1.3

Subgroups	Number of Respondents (%)
Provider Analysis Set	124 (100.0%)
Primary Care Provider	6 (4.8%)
Diabetes Specialist Provider	25 (20.2%)
Eye Care Professional	79 (63.7%)
Ophthalmologist	78 (62.9%)

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

### PT 1.4

Item	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
What is your specialty?	General primary care/Family practitioner	6 (100.0%)	3 (12.0%)	0 (0.0%)	9 (7.3%)
	Diabetes specialist	0 (0.0%)	25 (100.0%)	0 (0.0%)	25 (20.2%)
	General ophthalmologist	0 (0.0%)	0 (0.0%)	56 (71.8%)	56 (45.2%)
	Optometrist	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (0.8%)
	Retinal specialist	0 (0.0%)	0 (0.0%)	33 (42.3%)	33 (26.6%)
	Nurse	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (0.8%)
	Health educator	0 (0.0%)	0 (0.0%)	0 (0.0%)	3 (2.4%)
	None of the above	0 (0.0%)	0 (0.0%)	0 (0.0%)	10 (8.1%)
	Total valid response	6 (100.0%)	25 (100.0%)	78 (100.0%)	124 (100.0%)
	Total missing	0	0	0	0

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 1.5

Item	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
How long have you been practicing in this profession?	Total valid response (n)	6	25	78	124
	Mean	23.0	18.9	15.3	15.1
	SD	16.6	10.2	8.8	10.1
	Median	16.5	20.0	13.0	13.5
	Min.	8	1	1	0
	Max.	52	40	40	52
	Total missing	0	0	0	0

### 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%)	17 (68.0%)	2 (2.6%)	20 (17.1%)
	Eye clinic/practice	0 (0.0%)	0 (0.0%)	63 (81.8%)	64 (54.7%)
	General medical clinic/practice	3 (60.0%)	6 (24.0%)	2 (2.6%)	11 (9.4%)
	Hospital	1 (20.0%)	2 (8.0%)	10 (13.0%)	14 (12.0%)
	Other	1 (20.0%)	0 (0.0%)	0 (0.0%)	8 (6.8%)
	Total Valid Response	5 (100.0%)	25 (100.0%)	77 (100.0%)	117 (100.0%)
	Total missing	1	0	1	7

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Where is your main practice located?	Urban setting	5 (100.0%)	25 (100.0%)	73 (94.8%)	113 (96.6%)
	Non-urban	0 (0.0%)	0 (0.0%)	4 (5.2%)	4 (3.4%)

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	setting				
	Total Valid Response	5 (100.0%)	25 (100.0%)	77 (100.0%)	117 (100.0%)
	Total missing	1	0	1	7

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
In which sector is your main practice?	Government	2 (40.0%)	5 (20.0%)	8 (10.4%)	20 (17.1%)
	Private	2 (40.0%)	15 (60.0%)	49 (63.6%)	68 (58.1%)
	Non profit	1 (20.0%)	1 (4.0%)	2 (2.6%)	6 (5.1%)
	Combined/mixed	0 (0.0%)	4 (16.0%)	18 (23.4%)	23 (19.7%)
	Total Valid Response	5 (100.0%)	25 (100.0%)	77 (100.0%)	117 (100.0%)
	Total missing	1	0	1	7

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Is your main practice limited to certain populations?	No	4 (80.0%)	18 (72.0%)	60 (77.9%)	89 (76.1%)
	Yes, limited by age	0 (0.0%)	3 (12.0%)	2 (2.6%)	5 (4.3%)
	Yes, limited to persons with health insurance	0 (0.0%)	2 (8.0%)	8 (10.4%)	10 (8.5%)
	Yes, limited to low income or uninsured persons	0 (0.0%)	0 (0.0%)	3 (3.9%)	4 (3.4%)



Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Yes, limited to persons who pay out-of-pocket	1 (20.0%)	2 (8.0%)	4 (5.2%)	8 (6.8%)
	Yes, other	0 (0.0%)	0 (0.0%)	4 (5.2%)	5 (4.3%)
	Total valid response	5 (100.0%)	25 (100.0%)	77 (100.0%)	117 (100.0%)
	Total missing	1	0	1	7

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	1 (25.0%)	3 (12.5%)	11 (15.9%)	16 (15.5%)
	More than 1 week but less than 1 month	1 (25.0%)	11 (45.8%)	37 (53.6%)	51 (49.5%)
	More than 1 month but less than 2 months	1 (25.0%)	3 (12.5%)	9 (13.0%)	14 (13.6%)
	More than 2 months but less than 3 months	1 (25.0%)	2 (8.3%)	4 (5.8%)	7 (6.8%)
	More than 3 months but less than 6 months	0 (0.0%)	5 (20.8%)	6 (8.7%)	11 (10.7%)
	Six or more months	0 (0.0%)	0 (0.0%)	1 (1.4%)	1 (1.0%)
	Other	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (1.0%)
	Don't know/Not sure	0 (0.0%)	0 (0.0%)	1 (1.4%)	2 (1.9%)
	Total Valid Response	4 (100.0%)	24 (100.0%)	69 (100.0%)	103 (100.0%)
	Total missing	2	1	9	21

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)	4	21	68	97
	Mean	64.5	54.5	104.4	91.1
	SD	24.2	30.3	89.5	80.3
	Median	55	40	100	80
	Min.	48	20	15	15
	Max.	100	120	700	700
	Total missing	2	4	10	27
What percentage of the patients in your main practice have diabetes [% patients]	Total valid response (n)	4	21	69	99
	Mean	33.8	58.3	29.2	35.9
	SD	27.5	23.5	18.9	24.2
	Median	27.5	50	25	30
	Min.	10	10	5	5
	Max.	70	90	80	90
	Total missing	2	4	9	25

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 (25.0%)	7 (30.4%)	12 (17.4%)	24 (23.3%)
	Pay a reduced/subsidized rate	0 (0.0%)	5 (21.7%)	19 (27.5%)	24 (23.3%)
	Pay out-of-pocket	0 (0.0%)	12 (52.2%)	34 (49.3%)	48



Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	(full fees)				(46.6%)
	Pay through insurance	0 (0.0%)	9 (39.1%)	46 (66.7%)	56 (54.4%)
	Patient pays some, insurance pays some	1 (25.0%)	3 (13.0%)	28 (40.6%)	33 (32.0%)
	Other	3 (75.0%)	1 (4.3%)	3 (4.3%)	9 (8.7%)
	Total valid response	4 (100.0%)	23 (100.0%)	69 (100.0%)	103 (100.0%)
	Total missing	2	2	9	21

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
In addition to your main practice, do you work in another practice setting?	Yes	1 (25.0%)	17 (70.8%)	37 (53.6%)	56 (53.3%)
	No	3 (75.0%)	7 (29.2%)	32 (46.4%)	49 (46.7%)
	Total valid response	4 (100.0%)	24 (100.0%)	69 (100.0%)	105 (100.0%)
	Total missing	2	1	9	19
In which other practice setting(s) do you work?	Hospital	1 (100.0%)	6 (40.0%)	13 (35.1%)	20 (37.0%)
	General medical clinic/practice		5 (33.3%)	3 (8.1%)	8 (14.8%)
	Diabetes clinic/practice		6 (40.0%)	1 (2.7%)	7 (13.0%)
	Eye clinic/practice			23 (62.2%)	23 (42.6%)
	Other			3 (8.1%)	4 (7.4%)
	Total valid response	1 (100.0%)	15 (100.0%)	37 (100.0%)	54 (100.0%)
	Total missing	5	10	41	70
In which sector(s) is(are) the	Government	1 (100.0%)	6 (40.0%)	10 (27.0%)	18 (33.3%)

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
practice(s)?					
	Private		7 (46.7%)	13 (35.1%)	20 (37.0%)
	Non profit		1 (6.7%)	1 (2.7%)	2 (3.7%)
	Combined/mixed		1 (6.7%)	13 (35.1%)	14 (25.9%)
	Total valid response	1 (100.0%)	15 (100.0%)	37 (100.0%)	54 (100.0%)
	Total missing	5	10	41	70
Is there a major difference between your practices with respect to how diabetic eye disease is screened and managed?	Yes	1 (100.0%)	9 (64.3%)	23 (62.2%)	33 (62.3%)
	No		5 (35.7%)	14 (37.8%)	20 (37.7%)
	Total valid response	1 (100.0%)	14 (100.0%)	37 (100.0%)	53 (100.0%)
	Total missing	5	11	41	71

Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Blood glucose	Yes		3 (75.0%)	17 (85.0%)	26 (48.1%)	49 (60.5%)
		Total valid numeric response (n)	3 (75.0%)	15 (75.0%)	23 (42.6%)	44 (54.3%)
		Mean	3.3	3.7	2.7	3.2
		SD	0.6	1.2	3.1	2.4
		Median	3.0	4.0	2.0	3.0
		Min	3	0	0	0
		Max	4	6	12	12
		Total missing	3	10	55	80



Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	No		1 (25.0%)	3 (15.0%)	28 (51.9%)	32 (39.5%)
	Total valid response		4 (100.0%)	20 (100.0%)	54 (100.0%)	81 (100.0%)
	Total missing		2	5	24	43
HbA1c	Yes		3 (75.0%)	15 (78.9%)	20 (39.2%)	38 (49.4%)
		Total valid numeric response (n)	3 (75.0%)	14 (73.7%)	17 (33.3%)	34 (44.2%)
		Mean	3.3	3.4	8.3	5.8
		SD	0.6	1.1	23.7	16.7
		Median	3.0	4.0	2.0	3.0
		Min	3	0	1	0
		Max	4	4	100	100
		Total missing	3	11	61	90
	No		1 (25.0%)	4 (21.1%)	31 (60.8%)	39 (50.6%)
	Total valid response		4 (100.0%)	19 (100.0%)	51 (100.0%)	77 (100.0%)
	Total missing		2	6	27	47
Urine check	Yes		4 (100.0%)	14 (73.7%)	8 (16.7%)	27 (36.5%)
		Total valid numeric response (n)	4 (100.0%)	13 (68.4%)	5 (10.4%)	23 (31.1%)
		Mean	3.0	1.9	1.2	2.0
		SD	1.4	1.1	0.8	1.2
		Median	3.5	2.0	1.0	2.0
		Min	1	0	0	0
		Max	4	4	2	4
		Total	2	12	73	101

Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
		missing				
	No			5 (26.3%)	40 (83.3%)	47 (63.5%)
	Total valid response		4 (100.0%)	19 (100.0%)	48 (100.0%)	74 (100.0%)
	Total missing		2	6	30	50
Weight check	Yes		4 (100.0%)	19 (95.0%)	11 (22.9%)	37 (49.3%)
		Total valid numeric response (n)	4 (100.0%)	16 (80.0%)	8 (16.7%)	31 (41.3%)
		Mean	5.5	3.8	3.5	4.3
		SD	4.4	1.3	3.8	2.9
		Median	3.5	4.0	3.0	4.0
		Min	3	0	0	0
		Max	12	6	12	12
		Total missing	2	9	70	93
	No		l	1 (5.0%)	37 (77.1%)	38 (50.7%)
	Total valid response		4 (100.0%)	20 (100.0%)	48 (100.0%)	75 (100.0%)
	Total missing		2	5	30	49
Blood pressure check	Yes		4 (100.0%)	19 (95.0%)	25 (50.0%)	51 (66.2%)
	'	Total valid numeric response (n)	4 (100.0%)	16 (80.0%)	22 (44.0%)	45 (58.4%)
		Mean	5.5	3.8	13.3	10.0
		SD	4.4	1.3	31.6	23.6
		Median	3.5	4.0	2.5	4.0
		Min	3	0	0	0
		Max	12	6	120	120



Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
		Total missing	2	9	56	79
	No			1 (5.0%)	25 (50.0%)	26 (33.8%)
	Total valid response		4 (100.0%)	20 (100.0%)	50 (100.0%)	77 (100.0%)
	Total missing		2	5	28	47
Foot check	Yes		2 (50.0%)	16 (80.0%)	7 (14.6%)	26 (34.7%)
		Total valid numeric response (n)	2 (50.0%)	13 (65.0%)	4 (8.3%)	20 (26.7%)
		Mean	3.0	2.5	1.8	2.6
		SD	0.0	2.8	1.0	2.5
		Median	3.0	1.0	1.5	2.0
		Min	3	0	1	0
		Max	3	11	3	11
		Total missing	4	12	74	104
	No		2 (50.0%)	4 (20.0%)	41 (85.4%)	49 (65.3%)
	Total valid response		4 (100.0%)	20 (100.0%)	48 (100.0%)	75 (100.0%)
	Total missing		2	5	30	49
Eye examination - Un-dilated	Yes		2 (50.0%)	4 (21.1%)	55 (90.2%)	63 (71.6%)
		Total valid numeric response (n)	2 (50.0%)	4 (21.1%)	52 (85.2%)	60 (68.2%)
		Mean	2.0	1.0	11.9	10.6
		SD	1.4	0.0	52.0	48.5
		Median	2.0	1.0	2.0	2.0
		Min	1	1	0	0

Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
		Max	3	1	365	365
		Total missing	4	21	26	64
	No		2 (50.0%)	15 (78.9%)	6 (9.8%)	25 (28.4%)
	Total valid response		4 (100.0%)	19 (100.0%)	61 (100.0%)	88 (100.0%)
	Total missing		2	6	17	36
Eye examination - Optical Coherence Tomography	Yes			2 (10.5%)	56 (87.5%)	58 (64.4%)
		Total valid numeric response (n)	0 (0.0%)	2 (10.5%)	52 (81.3%)	54 (60.0%)
		Mean		0.0	22.6	21.8
		SD		0.0	85.6	84.0
		Median		0.0	1.0	1.0
		Min		0	0	0
		Max		0	365	365
		Total missing	6	23	26	70
	No		4 (100.0%)	17 (89.5%)	8 (12.5%)	32 (35.6%)
	Total valid response		4 (100.0%)	19 (100.0%)	64 (100.0%)	90 (100.0%)
	Total missing		2	6	14	34
Eye examination - Fundoscopy	Yes		2 (50.0%)	7 (36.8%)	65 (100.0%)	75 (81.5%)
		Total valid numeric response (n)	2 (50.0%)	6 (31.6%)	61 (93.8%)	70 (76.1%)
		Mean	1.5	1.0	20.5	18.1



Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
		SD	0.7	0.0	79.1	74.0
		Median	1.5	1.0	2.0	2.0
		Min	1	1	0	0
		Max	2	1	365	365
		Total missing	4	19	17	54
	No		2 (50.0%)	12 (63.2%)		17 (18.5%)
	Total valid response		4 (100.0%)	19 (100.0%)	65 (100.0%)	92 (100.0%)
	Total missing		2	6	13	32
Eye examination - Fluorescein Angiography	Yes		1 (25.0%)	3 (15.8%)	59 (89.4%)	63 (68.5%)
		Total valid numeric response (n)	1 (25.0%)	3 (15.8%)	54 (81.8%)	58 (63.0%)
		Mean	1.0	0.7	18.5	17.2
		SD		0.6	73.7	71.2
		Median	1.0	1.0	1.0	1.0
		Min	1	0	0	0
		Max	1	1	365	365
		Total missing	5	22	24	66
	No		3 (75.0%)	16 (84.2%)	7 (10.6%)	29 (31.5%)
	Total valid response		4 (100.0%)	19 (100.0%)	66 (100.0%)	92 (100.0%)
	Total missing		2	6	12	32
Eye examination - Lipid check	Yes		1 (25.0%)	4 (21.1%)	19 (38.0%)	25 (32.9%)
	1	Total valid	1 (25.0%)	4 (21.1%)	17 (34.0%)	23

Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
		numeric response (n)				(30.3%)
		Mean	4.0	1.0	1.5	1.7
		SD		0.0	1.0	1.4
		Median	4.0	1.0	1.0	1.0
		Min	4	1	0	0
		Max	4	1	3	6
		Total missing	5	21	61	101
	No		3 (75.0%)	15 (78.9%)	31 (62.0%)	51 (67.1%)
	Total valid response		4 (100.0%)	19 (100.0%)	50 (100.0%)	76 (100.0%)
	Total missing		2	6	28	48

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	4 (100.0%)	15 (100.0%)	47 (77.0%)	68 (80.0%)
	Diet/nutrition	4 (100.0%)	15 (100.0%)	35 (57.4%)	57 (67.1%)
	Exercise/physical activity	4 (100.0%)	15 (100.0%)	37 (60.7%)	59 (69.4%)
	Medicines	4 (100.0%)	15 (100.0%)	43 (70.5%)	65 (76.5%)
	Foot care and inspection	4 (100.0%)	15 (100.0%)	4 (6.6%)	26 (30.6%)
	Blood pressure	4 (100.0%)	14 (93.3%)	22 (36.1%)	42 (49.4%)
	Eye care and	3 (75.0%)	11 (73.3%)	53 (86.9%)	70



Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	exams				(82.4%)
	Lipid check	4 (100.0%)	14 (93.3%)	11 (18.0%)	31 (36.5%)
	None of the above	0 (0.0%)	0 (0.0%)	1 (1.6%)	2 (2.4%)
	Total valid response	4 (100.0%)	15 (100.0%)	61 (100.0%)	85 (100.0%)
	Total missing	2	10	17	39

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%)	3 (18.8%)	18 (29.5%)	23 (26.7%)
	Yes, but information on eye complications is not sufficient	1 (25.0%)	3 (18.8%)	7 (11.5%)	12 (14.0%)
	Yes, but no information on eye complications is included	1 (25.0%)	3 (18.8%)	1 (1.6%)	5 (5.8%)
	No written information is available for patients	2 (50.0%)	6 (37.5%)	31 (50.8%)	41 (47.7%)
Don't know/Not sure		0 (0.0%)	1 (6.3%)	4 (6.6%)	5 (5.8%)
	Total Valid Response	4 (100.0%)	16 (100.0%)	61 (100.0%)	86 (100.0%)
	Total missing	2	9	17	38

Question	Response	Primary Care	Diabetes Specialist	Ophthalmologist	PAS
		Provider	Provider		

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	1 (25.0%)	4 (25.0%)	17 (27.9%)	24 (28.2%)
	Yes, available but not used by staff	0 (0.0%)	4 (25.0%)	5 (8.2%)	9 (10.6%)
	Not available	3 (75.0%)	7 (43.8%)	36 (59.0%)	48 (56.5%)
	Don't know/Not sure	0 (0.0%)	1 (6.3%)	3 (4.9%)	4 (4.7%)
	Total Valid Response	4 (100.0%)	16 (100.0%)	61 (100.0%)	85 (100.0%)
	Total missing	2	9	17	39

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	0 (0.0%)	5 (31.3%)	23 (38.3%)	29 (34.5%)
	Yes, available but not used by staff	1 (25.0%)	2 (12.5%)	5 (8.3%)	8 (9.5%)
	Not available	3 (75.0%)	9 (56.3%)	30 (50.0%)	45 (53.6%)
	Don't know/Not sure	0 (0.0%)	0 (0.0%)	2 (3.3%)	2 (2.4%)
	Total Valid	4	16	60 (100.0%)	84



Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Response	(100.0%)	(100.0%)		(100.0%)
	Total missing	2	9	18	40

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
What is the protocol in your main practice for timing of initial eye exams for persons with diabetes - Type I?	After a predetermined number of years (numeric response) (n)	1 (25.0%)	8 (53.3%)	12 (20.7%)	21 (25.6%)
	Mean	5.0	4.8	5.0	4.9
	SD		0.7	1.9	1.4
	Median	5.0	5.0	5.0	5.0
	Min	5	3	2	2
	Max	5	5	10	10
	After a predetermined age (numeric response) (n)	0 (0.0%)	1 (6.7%)	1 (1.7%)	2 (2.4%)
	Mean		10.0	50.0	30.0
	SD	1			28.3
	Median	1	10.0	50.0	30.0
	Min	1	10	50	10
	Max	1	10	50	50
	As soon as they are diagnosed	2 (50.0%)	4 (26.7%)	37 (63.8%)	45 (54.9%)
	When a patient reports eye/vision problems		1	2 (3.4%)	4 (4.9%)
	No standard practice, timing varies case by case	1 (25.0%)	1 (6.7%)	4 (6.9%)	6 (7.3%)
	Don't know/Not		1	1 (1.7%)	2 (2.4%)

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	sure				
	Other		1 (6.7%)	1 (1.7%)	2 (2.4%)
	Total valid response	4 (100.0%)	15 (100.0%)	58 (100.0%)	82 (100.0%)
	Total missing	2	10	20	42
What is the protocol in your main practice for timing of initial eye exams for persons with diabetes - Type II?	After a predetermined number of years (numeric response) (n)	0 (0.0%)	0 (0.0%)	5 (8.5%)	5 (6.1%)
	Mean			4.6	4.6
	SD	•		0.5	0.5
	Median	•		5.0	5.0
	Min	•		4	4
	Max	-		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	3 (75.0%)	14 (93.3%)	48 (81.4%)	67 (81.7%)
	When a patient reports eye/vision problems		1	3 (5.1%)	4 (4.9%)
	No standard practice, timing varies case by case	1 (25.0%)	1 (6.7%)	3 (5.1%)	5 (6.1%)
	Don't know/Not sure		1	•	1 (1.2%)
	Total valid response	4 (100.0%)	15 (100.0%)	59 (100.0%)	82 (100.0%)



Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Total missing	2	10	19	42

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 with diabetes?	Once a year	2 (50.0%)	13 (92.9%)	50 (86.2%)	68 (84.0%)
	Every two years	0 (0.0%)	1 (7.1%)	1 (1.7%)	2 (2.5%)
	More than every two years	1 (25.0%)	0 (0.0%)	0 (0.0%)	1 (1.2%)
	Only when symptoms are present	0 (0.0%)	0 (0.0%)	2 (3.4%)	3 (3.7%)
	Other	0 (0.0%)	0 (0.0%)	5 (8.6%)	5 (6.2%)
	Don't know/Not sure	1 (25.0%)	0 (0.0%)	0 (0.0%)	2 (2.5%)
	Total Valid Response	4 (100.0%)	14 (100.0%)	58 (100.0%)	81 (100.0%)
	Total missing	2	11	20	43

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Do you screen patients for DR?	Yes	2 (50.0%)	5 (35.7%)	56 (96.6%)	64 (79.0%)
	No	2 (50.0%)	9 (64.3%)	2 (3.4%)	17 (21.0%)
	Total valid response	4 (100.0%)	14 (100.0%)	58 (100.0%)	81 (100.0%)
	Total missing	2	11	20	43

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Where do you screen patients?	In clinic	2 (100.0%)	2 (40.0%)	53 (94.6%)	57 (90.5%)
	Outreach		1 (20.0%)	3 (5.4%)	4 (6.3%)
	Other	1 (50.0%)	3 (60.0%)	3 (5.4%)	7 (11.1%)
	Total valid response	2 (100.0%)	5 (100.0%)	56 (100.0%)	63 (100.0%)
	Total missing	4	20	22	61

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
What patient characteristics influence your vision care and/or vision referrals?	Diabetes duration	3 (75.0%)	12 (92.3%)	49 (90.7%)	66 (89.2%)
	Patient's age	2 (50.0%)	8 (61.5%)	26 (48.1%)	37 (50.0%)
	Patient's gender	0 (0.0%)	1 (7.7%)	0 (0.0%)	1 (1.4%)
	Presence of comorbidities such as hypertension, etc.	3 (75.0%)	12 (92.3%)	38 (70.4%)	56 (75.7%)
	High glucose levels	2 (50.0%)	10 (76.9%)	41 (75.9%)	56 (75.7%)
	Ability or inability to pay	0 (0.0%)	1 (7.7%)	5 (9.3%)	6 (8.1%)
	Insurance restrictions	0 (0.0%)	2 (15.4%)	4 (7.4%)	6 (8.1%)
	Patient educational level	2 (50.0%)	1 (7.7%)	2 (3.7%)	5 (6.8%)
	Patient adherence to recommendations	1 (25.0%)	2 (15.4%)	8 (14.8%)	11 (14.9%)
	None of the above	1 (25.0%)	0 (0.0%)	0 (0.0%)	1 (1.4%)
	Not applicable	0 (0.0%)	1 (7.7%)	4 (7.4%)	5 (6.8%)
	Total valid response	4 (100.0%)	13 (100.0%)	54 (100.0%)	74 (100.0%)
	Total missing	2	12	24	50



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	2 (50.0%)	4 (30.8%)	40 (74.1%)	47 (63.5%)
	Proximity to care	1 (25.0%)	1 (7.7%)	14 (25.9%)	16 (21.6%)
	Long wait time for appointment	2 (50.0%)	6 (46.2%)	13 (24.1%)	22 (29.7%)
	Long wait time on the day of visit	1 (25.0%)	1 (7.7%)	4 (7.4%)	6 (8.1%)
	Referral process	2 (50.0%)	5 (38.5%)	16 (29.6%)	24 (32.4%)
	Recommended treatments are not available	1 (25.0%)	2 (15.4%)	9 (16.7%)	13 (17.6%)
	Lack of knowledge and/or awareness	3 (75.0%)	2 (15.4%)	35 (64.8%)	41 (55.4%)
	Patients fear of treatment/results	0 (0.0%)	2 (15.4%)	17 (31.5%)	19 (25.7%)
	Patients they are a burden on family/friends	0 (0.0%)	0 (0.0%)	3 (5.6%)	3 (4.1%)
	Limited access to diabetes specialists	1 (25.0%)	0 (0.0%)	22 (40.7%)	25 (33.8%)
	Limited access to eye specialists	3 (75.0%)	4 (30.8%)	14 (25.9%)	23 (31.1%)
	Patients feel eye complications are unlikely	1 (25.0%)	5 (38.5%)	19 (35.2%)	25 (33.8%)
	Patients feel eye exams are not important	2 (50.0%)	3 (23.1%)	16 (29.6%)	21 (28.4%)
	Patients have competing responsibilities and	0 (0.0%)	3 (23.1%)	9 (16.7%)	12 (16.2%)

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	priorities				
	Clinic too small or lack necessary equipment/staff	1 (25.0%)	2 (15.4%)	2 (3.7%)	7 (9.5%)
	Other	0 (0.0%)	0 (0.0%)	3 (5.6%)	3 (4.1%)
	Total valid response	4 (100.0%)	13 (100.0%)	54 (100.0%)	74 (100.0%)
	Total missing	2	12	24	50

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 (50.0%)	8 (61.5%)	35 (63.6%)	49 (64.5%)
	No	2 (50.0%)	4 (30.8%)	18 (32.7%)	24 (31.6%)
	Don't know/Not sure	0 (0.0%)	1 (7.7%)	2 (3.6%)	3 (3.9%)
	Total Valid Response	4 (100.0%)	13 (100.0%)	55 (100.0%)	76 (100.0%)
	Total missing	2	12	23	48

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, podiastrist?	Yes	3 (75.0%)	9 (69.2%)	52 (96.3%)	67 (90.5%)
	No	1 (25.0%)	4 (30.8%)	2 (3.7%)	7 (9.5%)
	Total Valid	4	13	54 (100.0%)	74



Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Response	(100.0%)	(100.0%)		(100.0%)
	Total missing	2	12	24	50

#### PT 3.1

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Please indicate your age:	18 - 29		1 (7.7%)		2 (2.6%)
	30 - 39	2 (50.0%)	2 (15.4%)	22 (40.0%)	26 (34.2%)
	40 - 49	1 (25.0%)	5 (38.5%)	20 (36.4%)	28 (36.8%)
	50 - 59		4 (30.8%)	8 (14.5%)	12 (15.8%)
	60 - 69			5 (9.1%)	6 (7.9%)
	70 - 79	1 (25.0%)	1 (7.7%)		2 (2.6%)
	Total valid response	4 (100.0%)	13 (100.0%)	55 (100.0%)	76 (100.0%)
	Total missing	2	12	23	48
What is your gender?	Female	2 (50.0%)	5 (38.5%)	20 (36.4%)	29 (38.2%)
	Male	2 (50.0%)	8 (61.5%)	35 (63.6%)	47 (61.8%)
	Total valid response	4 (100.0%)	13 (100.0%)	55 (100.0%)	76 (100.0%)
	Total missing	2	12	23	48
What is your highest level of education completed?	College/University	1 (25.0%)	2 (15.4%)	10 (18.2%)	14 (18.4%)
	Graduate or advanced degree (e.g. PhD, MD, etc)	3 (75.0%)	11 (84.6%)	45 (81.8%)	62 (81.6%)
	Total valid response	4 (100.0%)	13 (100.0%)	55 (100.0%)	76 (100.0%)
	Total missing	2	12	23	48

Question	Response	Ophthalmologist
What percentage of your patients have diabetic retinopathy	Total valid numeric response (n)	55
	Mean	24.4
	SD	19.7
	Median	20.0
	Min	0
	Max	80
	Total missing	23

### PT 4.2

Question	Response	Ophthalmologist
What percentage of your patients have diabetic macular edema?	Total valid numeric response (n)	55
	Mean	15.9
	SD	16.6
	Median	10.0
	Min	0
	Max	60
	Total missing	23

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	13 (23.6%)
	More than 1 week but less than 1 month	26 (47.3%)
	More than 1 month but less than 2 months	6 (10.9%)
	More than 2 months but less than 3 months	4 (7.3%)
	More than 3 months but less than 6	2 (3.6%)



Question	Response	Ophthalmologist
	months	
	Six or more months	2 (3.6%)
	Don't know/Not sure	2 (3.6%)
	Total Valid Response	55 (100.0%)
	Total missing	23

Question	Response	Ophthalmologist
From the time a patient is screened, what is the average length of time he/she waits for diagnosis?	Less than 1 week	16 (29.1%)
	More than 1 week but less than 1 month	6 (10.9%)
	More than 3 months but less than 6 months	1 (1.8%)
	There is not wait, diagnosis is given when screened	32 (58.2%)
	Total Valid Response	55 (100.0%)
	Total missing	23

Type of Treatment	Question	Response/time	Ophthalmologist
Laser photocoagulation	Is the treatment available?	Available within country	20 (36.4%)
		Available locally	23 (41.8%)
		Available in practice	48 (87.3%)
		Not available	1 (1.8%)
		Total valid response	55 (100.0%)
		Total missing	23
	What is the average amount of time your patients wait for a consultation appointment? (weeks)	Total valid numeric response (n)	34 (79.1%)
		Mean	1.9
		SD	1.9
		Median	1.0

Type of Treatment	Question	Response/time	Ophthalmologist
		Min	0
		Max	8
		Don't know/not sure	6 (14.0%)
		Not applicable	3 (7.0%)
		Total valid response	43 (100.0%)
		Total missing	35
	What is the average amount of time your patients wait for a first treatment?(weeks)	Total valid numeric response (n)	38 (84.4%)
		Mean	1.6
		SD	1.1
		Median	1.0
		Min	0
		Max	4
		Don't know/not sure	4 (8.9%)
		Not applicable	3 (6.7%)
		Total valid response	45 (100.0%)
		Total missing	33
	What is the average amount of time your patients wait for a second treatment?(weeks)	Total valid numeric response (n)	35 (85.4%)
		Mean	2.4
		SD	1.6
		Median	2.0
		Min	0
		Max	8
		Don't know/not sure	4 (9.8%)
		Not applicable	2 (4.9%)
		Total valid response	41 (100.0%)
		Total missing	37
Anti-VEGF therapies	Is the treatment available?	Available within	20 (36.4%)



Type of Treatment	Question	Response/time	Ophthalmologist
		country	
		Available locally	24 (43.6%)
		Available in practice	44 (80.0%)
		Not available	2 (3.6%)
		Total valid response	55 (100.0%)
		Total missing	23
	What is the average amount of time your patients wait for a consultation appointment? (weeks)	Total valid numeric response (n)	33 (80.5%)
		Mean	2.3
		SD	2.4
		Median	1.0
		Min	0
		Max	12
		Don't know/not sure	6 (14.6%)
		Not applicable	2 (4.9%)
		Total valid response	41 (100.0%)
		Total missing	37
	What is the average amount of time your patients wait for a first treatment?(weeks)	Total valid numeric response (n)	36 (85.7%)
		Mean	2.2
		SD	2.6
		Median	1.0
		Min	0
		Max	12
		Don't know/not sure	3 (7.1%)
		Not applicable	3 (7.1%)
		Total valid response	42 (100.0%)
		Total missing	36
	What is the average amount of time	Total valid numeric	33 (84.6%)

Type of Treatment	Question	Response/time	Ophthalmologist
	your patients wait for a second treatment?(weeks)	response (n)	
		Mean	3.5
		SD	2.4
		Median	4.0
		Min	0
		Max	12
		Don't know/not sure	4 (10.3%)
		Not applicable	2 (5.1%)
		Total valid response	39 (100.0%)
		Total missing	39
Intravitreal steroid	Is the treatment available?	Available within country	19 (35.2%)
		Available locally	22 (40.7%)
		Available in practice	44 (81.5%)
		Not available	3 (5.6%)
		Total valid response	54 (100.0%)
		Total missing	24
	What is the average amount of time your patients wait for a consultation appointment? (weeks)	Total valid numeric response (n)	31 (79.5%)
		Mean	2.1
		SD	2.2
		Median	1.0
		Min	0
		Max	12
		Don't know/not sure	5 (12.8%)
		Not applicable	3 (7.7%)
		Total valid response	39 (100.0%)
		Total missing	39
	What is the average amount of time	Total valid numeric	34 (85.0%)



Type of Treatment	Question	Response/time	Ophthalmologist
	your patients wait for a first treatment?(weeks)	response (n)	
		Mean	2.0
		SD	2.1
		Median	1.0
		Min	0
		Max	12
		Don't know/not sure	3 (7.5%)
		Not applicable	3 (7.5%)
		Total valid response	40 (100.0%)
		Total missing	38
	What is the average amount of time your patients wait for a second treatment?(weeks)	Total valid numeric response (n)	28 (75.7%)
		Mean	6.0
		SD	6.5
		Median	4.0
		Min	1
		Max	24
		Don't know/not sure	6 (16.2%)
		Not applicable	3 (8.1%)
		Total valid response	37 (100.0%)
		Total missing	41
Uncomplicated vitrectomy	Is the treatment available?	Available within country	20 (37.0%)
		Available locally	27 (50.0%)
		Available in practice	40 (74.1%)
		Not available	2 (3.7%)
		Total valid response	54 (100.0%)
		Total missing	24
	What is the average amount of time	Total valid numeric	32 (80.0%)

Type of Treatment	Question	Response/time	Ophthalmologist
	your patients wait for a consultation appointment? (weeks)	response (n)	
		Mean	3.8
		SD	5.2
		Median	2.0
		Min	0
		Max	20
		Don't know/not sure	6 (15.0%)
		Not applicable	2 (5.0%)
		Total valid response	40 (100.0%)
		Total missing	38
	What is the average amount of time your patients wait for a first treatment?(weeks)	Total valid numeric response (n)	34 (82.9%)
		Mean	3.8
		SD	4.8
		Median	2.0
		Min	0
		Max	20
		Don't know/not sure	4 (9.8%)
		Not applicable	3 (7.3%)
		Total valid response	41 (100.0%)
		Total missing	37
	What is the average amount of time your patients wait for a second treatment?(weeks)	Total valid numeric response (n)	28 (73.7%)
	L	Mean	3.6
		SD	3.2
		Median	3.0
		Min	0
		Max	16
		Don't know/not sure	5 (13.2%)



Type of Treatment	Question	Response/time	Ophthalmologist
		Not applicable	5 (13.2%)
		Total valid response	38 (100.0%)
		Total missing	40
Complex vitreo- retinal surgery	Is the treatment available?	Available within country	21 (38.9%)
		Available locally	25 (46.3%)
		Available in practice	41 (75.9%)
		Not available	2 (3.7%)
		Total valid response	54 (100.0%)
		Total missing	24
	What is the average amount of time your patients wait for a consultation appointment? (weeks)	Total valid numeric response (n)	31 (77.5%)
		Mean	3.8
		SD	5.1
		Median	2.0
		Min	0
		Max	20
		Don't know/not sure	6 (15.0%)
		Not applicable	3 (7.5%)
		Total valid response	40 (100.0%)
		Total missing	38
	What is the average amount of time your patients wait for a first treatment?(weeks)	Total valid numeric response (n)	33 (80.5%)
		Mean	3.9
		SD	4.8
		Median	2.0
		Min	0
		Max	20
		Don't know/not sure	4 (9.8%)

Type of Treatment	Question	Response/time	Ophthalmologist
		Not applicable	4 (9.8%)
		Total valid response	41 (100.0%)
		Total missing	37
	What is the average amount of time your patients wait for a second treatment?(weeks)	Total valid numeric response (n)	28 (71.8%)
		Mean	4.1
		SD	3.5
		Median	4.0
		Min	0
		Max	16
		Don't know/not sure	5 (12.8%)
		Not applicable	6 (15.4%)
		Total valid response	39 (100.0%)
		Total missing	39

Question	Response	Ophthalmologist
Do you personally administer treatment for diabetic retinopathy?	Yes	48 (88.9%)
	No	6 (11.1%)
	Total valid response	54 (100.0%)
	Total missing	24
Who administer it?	Another provider in your practice	2 (33.3%)
	Refer to a provider at another facility	3 (50.0%)
	Other	1 (16.7%)
	Total valid response	6 (100.0%)
	Total missing	72

Question	Response	Ophthalmologist



Question	Response	Ophthalmologist
Do any of the following influence how you treat diabetic retinopathy or diabetic macular edema?	Diabetes duration	16 (44.4%)
	Patient's age	7 (19.4%)
	Patient's gender	5 (13.9%)
	Presence of comorbidities such as hypertension, etc.	12 (33.3%)
	High glucose levels	19 (52.8%)
	Ability or inability to pay	7 (19.4%)
	Insurance restrictions	4 (11.1%)
	Patient educational level	6 (16.7%)
	Patient adherence to recommendations	11 (30.6%)
	None of the above	6 (16.7%)
	Total valid response	36 (100.0%)
	Total missing	42

Question	Response	Ophthalmologist
Do you treat diabetic retinopathy and diabetic macular edema based on:	Anatomical outcomes	3 (5.7%)
	Both	49 (92.5%)
	Other	1 (1.9%)
	Total Valid Response	53 (100.0%)
	Total missing	25

Question	Response	Ophthalmologist
How are your patients with diabetes screened for diabetic eye disease?	Fundoscopy undilated	5 (9.4%)
	Fundoscopy dilated	51 (96.2%)
	Retinal photo	28 (52.8%)
	Optical Coherence Tomography	31 (58.5%)
	Fluorescein Angiography	32 (60.4%)

Question	Response	Ophthalmologist
	Total valid response	53 (100.0%)
	Total missing	25

Question	Response	Ophthalmologist
In your opinion, do the majority of your patients present:	In time for screening	7 (13.2%)
	When visual problems have already occurred	42 (79.2%)
	Too late for effective treatment	4 (7.5%)
	Total Valid Response	53 (100.0%)
	Total missing	25

## 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	48 (94.1%)
	No	3 (5.9%)
	Total valid response	51 (100.0%)
	Total missing	27
If yes, When was your last training?	Five or more years ago	15 (31.3%)
	Greater than 1 year ago but less than 5 years	10 (20.8%)
	Within the past year	23 (47.9%)
	Total valid response	48 (100.0%)
	Total missing	30

Question	Response	Ophthalmologist
Would you be interested in online education and certification on DME, Angiogenesis and Anti-VEGF therapies?	Yes	37 (72.5%)
	No	14 (27.5%)
	Total Valid	51 (100.0%)



Question	Response	Ophthalmologist
	Response	
	Total missing	27

Question	Response	Ophthalmologist
How is outreach for screening for diabetic eye disease done in your main practice?	Health fairs for all	9 (19.1%)
	Health fairs for people with diabetes	4 (8.5%)
	Mobile screening centers	14 (29.8%)
	At vision centers	14 (29.8%)
	Other	6 (12.8%)
	Not done	12 (25.5%)
	Don't know/Not sure	2 (4.3%)
	Total valid response	47 (100.0%)
	Total missing	31

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	28 (56.0%)
	Late diagnosis	38 (76.0%)
	Referral pathways	23 (46.0%)
	Limited access to patient education on diabetic retinopathy and diabetic macular edema	34 (68.0%)
	No universal guidelines on referral/screening	12 (24.0%)
	No universal guidelines on how to treat	9 (18.0%)
	No universal guideline on when to treat	5 (10.0%)
	Current available therapies not effective	2 (4.0%)
	Government/insurance not able to cover patient costs	26 (52.0%)
	Multi-disciplinary team integration is poor	18 (36.0%)

Question	Response	Ophthalmologist
	Ineffective screening services	14 (28.0%)
	Other	2 (4.0%)
	Total valid response	50 (100.0%)
	Total missing	28

#### EXP 1

Question	Response	Without DED (%)	With DED (%)	With DME (%)
Which of the following complications of diabetes do you have?	Cardiovascular disease/Stroke	2 (2.6%)	1 (2.8%)	1 (11.1%)
	Loss of feeling in hands or toes (neuropathy)	3 (3.9%)	4 (11.1%)	1 (11.1%)
	Vision loss	5 (6.5%)	19 (52.8%)	7 (77.8%)
	Foot ulcers	1 (1.3%)	1 (2.8%)	0 (0.0%)
	Irritable bowel disease	4 (5.2%)	4 (11.1%)	0 (0.0%)
	Kidney disease	1 (1.3%)	5 (13.9%)	0 (0.0%)
	Amputation	1 (1.3%)	0 (0.0%)	0 (0.0%)
	Other	2 (2.6%)	2 (5.6%)	0 (0.0%)
	None	57 (74.0%)	8 (22.2%)	2 (22.2%)
	Don't know/Not sure	5 (6.5%)	0 (0.0%)	0 (0.0%)
	Total Valid Response	77 (100.0%)	36 (100.0%)	9 (100.0%)
	Total missing	15	2	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".

Limitations	Without DED n (%)	With DED n (%)	With DME n (%)
Limited in any way in any activities because of impairment or health problem	13 (17.6%)	14 (36.8%)	7 (77.8%)
Impairment or health problem			
Diabetes	10 (83.3%)	8 (61.5%)	5 (83.3%)
Back or neck problem	4 (40.0%)	5 (41.7%)	2 (40.0%)

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

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



Limitations	Without DED n (%)	With DED n (%)	With DME n (%)
Mental or emotional health	3 (33.3%)	2 (16.7%)	2 (40.0%)
Walking problem	2 (25.0%)	6 (50.0%)	2 (40.0%)
Lung/breathing problem	2 (25.0%)	2 (16.7%)	0 (0.0%)
Eye/vision problem	2 (22.2%)	11 (73.3%)	6 (100.0%)
Heart problem	2 (22.2%)	1 (8.3%)	1 (20.0%)
Fractures, bone/joint injury	1 (12.5%)	5 (45.5%)	1 (25.0%)
Hypertension/high blood pressure	1 (12.5%)	4 (33.3%)	3 (50.0%)
Arthritis/rheumatism	0 (0.0%)	8 (66.7%)	2 (40.0%)
Cancer	0 (0.0%)	1 (8.3%)	0 (0.0%)
Hearing problem	0 (0.0%)	4 (33.3%)	0 (0.0%)

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

#### EXP 3

Health Status	Without DED (%)	With DED (%)	With DME (%)
Self-rated health: Good	50 (67.6%)	22 (64.7%)	5 (55.6%)
Self-rated health: Poor	24 (32.4%)	12 (35.3%)	4 (44.4%)
Physically unhealthy days	18 (29.5%)	9 (32.1%)	2 (25.0%)
Mentally unhealthy days	26 (42.6%)	9 (32.1%)	1 (20.0%)
Unhealthy days	34 (58.6%)	15 (53.6%)	2 (40.0%)
Activity limitation days	16 (36.4%)	7 (36.8%)	0 (0.0%)

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

Item	Response	All respondents	Respondents with Type I diabetes	Respondents with Type II diabetes
How do you manage your diabetes?	Diet	91 (67.9%)	45 (60.0%)	43 (78.2%)
	Oral medicine	53 (39.6%)	13 (17.3%)	37 (67.3%)
	Exercise	61 (45.5%)	39 (52.0%)	22 (40.0%)
	Insulin	95 (70.9%)	71 (94.7%)	22 (40.0%)
	Natural/Herbal medicine	2 (1.5%)	1 (1.3%)	1 (1.8%)

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

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

Item	Response	All respondents	Respondents with Type I diabetes	Respondents with Type II diabetes
	None of the above	2 (1.5%)	1 (1.3%)	

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	48 (64.9%)	23 (60.5%)	6 (66.7%)
	Working without pay at home (e.g. housework, farming)	3 (4.1%)	2 (5.3%)	1 (11.1%)
	Volunteering	1 (1.4%)	0 (0.0%)	0 (0.0%)
	Retired	4 (5.4%)	9 (23.7%)	1 (11.1%)
	Student	6 (8.1%)	2 (5.3%)	0 (0.0%)
	Not working	12 (16.2%)	2 (5.3%)	1 (11.1%)
	Total Valid Response	74 (100.0%)	38 (100.0%)	9 (100.0%)
	Total missing	18	0	0
Do you receive assistance from the government?	Income assistance	1 (1.4%)	3 (7.9%)	1 (14.3%)
	Medical assistance	19 (26.0%)	12 (31.6%)	3 (42.9%)
	Food assistance	0 (0.0%)	1 (2.6%)	0 (0.0%)
	Pension assistance	1 (1.4%)	5 (13.2%)	0 (0.0%)
	None of the above	53 (72.6%)	21 (55.3%)	3 (42.9%)
	Total valid response	73 (100.0%)	38 (100.0%)	7 (100.0%)
	Total missing	19	0	2
Did you have trouble paying for food at anytime during the past year?	Yes	18 (24.3%)	12 (32.4%)	5 (55.6%)
	No	56 (75.7%)	25 (67.6%)	4 (44.4%)
	Total Valid Response	74 (100.0%)	37 (100.0%)	9 (100.0%)
	Total missing	18	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	19 (52.8%)	19 (82.6%)	5 (83.3%)
	Working without pay at home (e.g. housework, farming)	2 (5.6%)	0 (0.0%)	0 (0.0%)
	Retired	0 (0.0%)	1 (4.3%)	0 (0.0%)
	Student	6 (16.7%)	2 (8.7%)	0 (0.0%)
	Not working	9 (25.0%)	1 (4.3%)	1 (16.7%)
	Total Valid Response	36 (100.0%)	23 (100.0%)	6 (100.0%)
	Total missing	7	0	0
Do you receive assistance from the government?	Income assistance	1 (2.9%)	0 (0.0%)	1 (16.7%)
	Medical assistance	14 (40.0%)	8 (34.8%)	2 (33.3%)
	None of the above	21 (60.0%)	15 (65.2%)	3 (50.0%)
	Total valid response	35 (100.0%)	23 (100.0%)	6 (100.0%)
	Total missing	8	0	0
Did you have trouble paying for food at anytime during the past year?	Yes	10 (27.8%)	7 (30.4%)	4 (66.7%)
	No	26 (72.2%)	16 (69.6%)	2 (33.3%)
	Total Valid Response	36 (100.0%)	23 (100.0%)	6 (100.0%)
	Total missing	7	0	0

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

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

Item	Response	Without	With DED	With DME
		DED (%)	(%)	(%)

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

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

Item	Response	Without DED (%)	With DED (%)	With DME (%)
Are you currently working?	Working for pay	22 (81.5%)	4 (66.7%)	1 (100.0%)
	Working without pay at home (e.g. housework, farming)	1 (3.7%)	1 (16.7%)	0 (0.0%)
	Volunteering	1 (3.7%)	0 (0.0%)	0 (0.0%)
	Not working	3 (11.1%)	1 (16.7%)	0 (0.0%)
	Total Valid Response	27 (100.0%)	6 (100.0%)	1 (100.0%)
	Total missing	9	0	0
Do you receive assistance from the government?	Medical assistance	4 (14.8%)	1 (16.7%)	1 (100.0%)
	Pension assistance	0 (0.0%)	1 (16.7%)	0 (0.0%)
	None of the above	23 (85.2%)	4 (66.7%)	0 (0.0%)
	Total valid response	27 (100.0%)	6 (100.0%)	1 (100.0%)
	Total missing	9	0	0
Did you have trouble paying for food at anytime during the past year?	Yes	6 (22.2%)	2 (40.0%)	0 (0.0%)
	No	21 (77.8%)	3 (60.0%)	1 (100.0%)
	Total Valid Response	27 (100.0%)	5 (100.0%)	1 (100.0%)
	Total missing	9	1	0

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

EXP 5.4: Age group 60-79 years

Item	Response	Without DED (%)	With DED (%)	With DME (%)
Are you currently working?	Working for pay	7 (70.0%)	0 (0.0%)	0 (0.0%)
	Working without pay at home (e.g. housework, farming)	0 (0.0%)	1 (12.5%)	1 (50.0%)
	Retired	3 (30.0%)	7 (87.5%)	1 (50.0%)
	Total Valid Response	10 (100.0%)	8 (100.0%)	2 (100.0%)

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

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



Item	Response	Without DED (%)	With DED (%)	With DME (%)
	Total missing	1	0	0
Do you receive assistance from the government?	Income assistance	0 (0.0%)	3 (37.5%)	0 (0.0%)
	Medical assistance	1 (10.0%)	3 (37.5%)	0 (0.0%)
	Food assistance	0 (0.0%)	1 (12.5%)	0 (0.0%)
	Pension assistance	1 (10.0%)	4 (50.0%)	0 (0.0%)
	None of the above	8 (80.0%)	1 (12.5%)	0 (0.0%)
	Total valid response	10 (100.0%)	8 (100.0%)	0
	Total missing	1	0	2
Did you have trouble paying for food at anytime during the past year?	Yes	2 (20.0%)	3 (37.5%)	1 (50.0%)
	No	8 (80.0%)	5 (62.5%)	1 (50.0%)
	Total Valid Response	10 (100.0%)	8 (100.0%)	2 (100.0%)
	Total missing	1	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 5.5: Age group 80+ years

Item	Response	Without DED (%)	With DED (%)	With DME (%)
Are you currently working?	Retired	1 (100.0%)	1 (100.0%)	0 (0.0%)
	Total Valid Response	1 (100.0%)	1 (100.0%)	0 (0.0%)
	Total missing	1	0	0
Do you receive assistance from the government?	None of the above	1 (100.0%)	1 (100.0%)	0 (0.0%)
	Total valid response	1 (100.0%)	1 (100.0%)	0
	Total missing	1	0	0
Did you have trouble paying for food at anytime during the past year?	No	1 (100.0%)	1 (100.0%)	0 (0.0%)
	Total Valid Response	1 (100.0%)	1 (100.0%)	0 (0.0%)
	Total missing	1	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".

Group	Subgroup	All respondents	Type 1 diabetes	Type 2 diabetes	With DED (%)	With DME (%)
All respondents		139 (100%)	79 (56.8%)	56 (40.3%)	38 (27.3%)	9 (6.5%)
Gender	Male	37 (30.6%)	13 (35.1%)	24 (64.9%)	10 (27.0%)	3 (8.1%)
	Female	84 (69.4%)	56 (66.7%)	26 (31.0%)	28 (33.3%)	6 (7.1%)
	Total Missing	18	10	6	0	0
Age	18-39 yrs	72 (51.8%)	59 (81.9%)	13 (18.1%)	23 (31.9%)	6 (8.3%)
	40-59 yrs	43 (30.9%)	14 (32.6%)	27 (62.8%)	6 (14.0%)	1 (2.3%)
	60-79 yrs	21 (15.1%)	6 (28.6%)	15 (71.4%)	8 (38.1%)	2 (9.5%)
	80 yrs and over	3 (2.2%)	0 (0.0%)	1 (33.3%)	1 (33.3%)	0 (0.0%)
Time since diagnosis	Within the last year	8 (5.8%)	2 (25.0%)	5 (62.5%)	3 (37.5%)	0 (0.0%)
	1 - 5 years ago	33 (23.9%)	12 (36.4%)	21 (63.6%)	5 (15.2%)	2 (6.1%)
	6 - 10 years ago	28 (20.3%)	11 (39.3%)	16 (57.1%)	9 (32.1%)	0 (0.0%)
	11 - 15 years ago	19 (13.8%)	13 (68.4%)	6 (31.6%)	3 (15.8%)	0 (0.0%)
	16 - 20 years ago	23 (16.7%)	17 (73.9%)	5 (21.7%)	8 (34.8%)	2 (8.7%)
	21 years ago or longer	26 (18.8%)	23 (88.5%)	3 (11.5%)	10 (38.5%)	5 (19.2%)
	Don't know/Not sure	1 (0.7%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	Total Missing	1	1	0	0	0
Control of Diabetes	Controlled	79 (59.8%)	39 (49.4%)	39 (49.4%)	21 (26.6%)	3 (3.8%)
	Not controlled	51 (38.6%)	35 (68.6%)	14 (27.5%)	17 (33.3%)	6 (11.8%)
	Don't know/Not sure	2 (1.5%)	0 (0.0%)	1 (50.0%)	0 (0.0%)	0 (0.0%)



Group	Subgroup	All respondents	Type 1 diabetes	Type 2 diabetes	With DED (%)	With DME (%)
	Total Missing	7	5	2	0	0

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

Question	Response	With DED n (%)	With DME n (%)
Have you had any treatment for diabetic eye disease?	Yes	34 (89.5%)	7 (87.5%)
	No	2 (5.3%)	1 (12.5%)
	Don't know/Not sure	2 (5.3%)	0 (0.0%)
	Total valid response	38 (100.0%)	8 (100.0%)
	Total missing	0	1
What treatment did you receive?	Laser	22 (66.7%)	6 (85.7%)
	Anti-VEGF	10 (30.3%)	5 (71.4%)
	Surgery	1 (3.0%)	3 (42.9%)
	Other	2 (6.1%)	0 (0.0%)
	Total valid response	33 (100.0%)	7 (100.0%)
	Total missing	5	2
Did you complete the treatment?	Yes	20 (58.8%)	3 (42.9%)
	No	4 (11.8%)	0 (0.0%)
	Still receiving treatment	9 (26.5%)	4 (57.1%)
	Don't know/Not sure	1 (2.9%)	0 (0.0%)
	Total valid response	34 (100.0%)	7 (100.0%)
	Total missing	4	2
Do you feel that the treatment worked?	Yes, and vision improved	20 (66.7%)	4 (57.1%)
	Yes, but vision stayed the same	4 (13.3%)	1 (14.3%)
	Still waiting to know	5 (16.7%)	2 (28.6%)
	Don't know/Not sure	1 (3.3%)	0 (0.0%)
	Total valid response	30 (100.0%)	7 (100.0%)

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

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

Question	Response	With DED n (%)	With DME n (%)
	Total missing	8	2
What is/are the reason(s) that you did not complete the treatment?	Treatment was too expensive	1 (25.0%)	0 (0.0%)
	Eye doctor was located too far away	1 (25.0%)	0 (0.0%)
	Appointment times were not convenient	1 (25.0%)	0 (0.0%)
	I was fearful (scared) of treatment	2 (50.0%)	0 (0.0%)
	Total valid response	4 (100.0%)	0 (0.0%)
	Total missing	34	9
What are the reason(s) that you have not had treatment for diabetic eye disease?	My doctor did not recommend any treatment	1 (100.0%)	1 (100.0%)
	Treatment is not accessible	0 (0.0%)	1 (100.0%)
	Still waiting for treatment	0 (0.0%)	1 (100.0%)
	Too expensive	0 (0.0%)	1 (100.0%)
	Total valid response	1 (100.0%)	1 (100.0%)
	Total missing	37	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.













