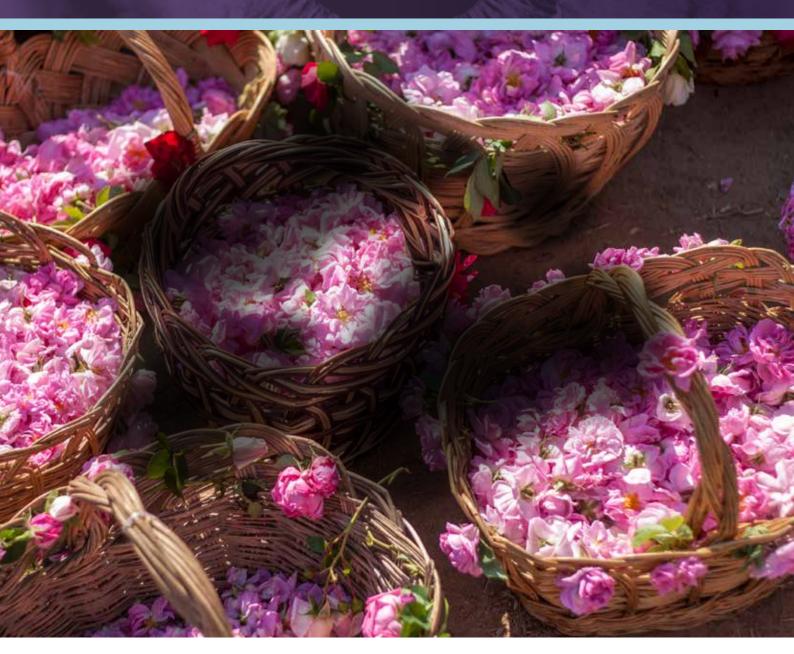


The Diabetic Retinopathy Barometer Report

# Bulgaria











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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 Bulgaria.

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

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

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

#### Goal

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

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

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

#### **Background**

The DR Barometer study used a mixed methods approach. Phase I was a qualitative study comprising 120 semi-structured interviews with a small sample of people with diabetes (n = 9 per country) and health care professionals (n = 6 per country) in each of 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 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, related national and international policies and the social and economic burden of the disease.

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

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

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

#### **Study Populations**

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

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

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

For the purpose of understanding the impact of the progression of diabetic eye disease 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 professionals.



## Introduction **Bulgaria Study**

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

Bulgaria is estimated to be the sixteenth most populous country in the European Union with a population of approximately 7.1 million.

Bulgaria is an ageing country with  $\sim 14\%$  of its population estimated to be under the age of 15 years while  $\sim 20\%$  over the age of 65 years.

Due to low fertility rates and an increasing life expectancy, Bulgaria's population is expected to experience a ~27% population decrease during the next few decades. By 2050, it is expected that the population will be 5.2 million with those under the age of 15 years making 15% of the total population and those aged 65 years and older 29% of the total population.

#### **Diabetes Profile<sup>2</sup>**

There are 415 million people living with diabetes worldwide and more than 59.8 million people are in the European Region. By 2040, this number is expected to rise to 71.1 million.

Bulgaria has over 459, 200 (356.5-644.7‡) adults living with diabetes, and a national prevalence (20 – 79 years) of 8.4% (6.5-11.7‡). Deaths attributed to diabetes in Bulgaria in 2015 were 7, 014 and the estimated number of undiagnosed cases was 199,000 (184.8-334.1‡).

#### **Study Populations: Bulgaria**

As reported by 30 respondents with diabetes in Bulgaria, 50% were diagnosed with DED and a further 20% with DME.

Ten health care professionals completed the survey in Bulgaria. Of these, one was a diabetes specialist provider (10%) and seven were ophthalmologists (70%). The remaining respondents were either nurses, health educators or other types of professionals.

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

The DR Barometer study was conducted in 41 countries. In Bulgaria, 30 adults with diabetes and 10 health care professionals provided new information about the experiences of living with, managing and treating diabetes, DR and DME.

41%

of patients said that the referral process being complicated or taking too long was a barrier to eye exams

33%

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



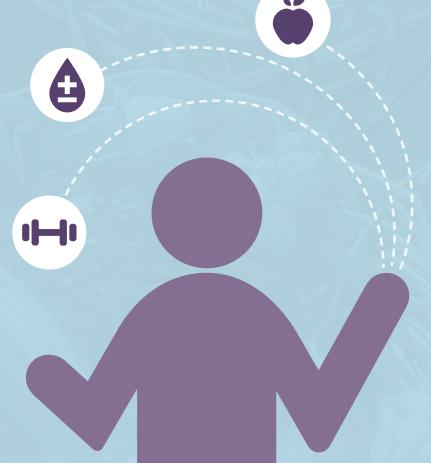








of respondents said their vision impairment due to DR or DME made it difficult to manage their diabetes







75%

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



17%

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



30%

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



# Bulgaria DR Barometer Findings:

#### **Adults with Diabetes**

### Key Demographic Characteristics

Thirty adults with diabetes completed the patients' survey in Bulgaria: 59% were female and 41% were male. Eighty-six percent lived in an urban setting and 14% in a non-urban setting (see Appendix Table 4.2).

The education level of respondents was as follows: 3% were educated to a primary school level, 41% to a secondary school level, 7% to a college or university level, and 48% to a graduate or post-graduate level (see Appendix Table 4.3).

Fifty-two percent of respondents were in paid employment, 24% were retired, and 10% were not working (see Appendix Table 4.4).

Forty-three percent of respondents were aged between 18 and 39 years (30% were 40-59 years, 23% were 60-79 years, and 3% were aged 80 and over). Seventy-three percent were of traditional working age (18-59 years) (see Table 1).

Of the respondents in Bulgaria, 77% had been diagnosed with type 1 diabetes and 23% with type 2 diabetes (see Appendix Table 2.1).

Fifty percent of those surveyed (n=15) had been diagnosed with DED and a further 20% (n=6) with DME.

Almost half of respondents (47%) were diagnosed with diabetes 21 years ago or more, 20% between 16 - 20 years ago, 13% 6 - 10 years and 11-15 years, and 3% between 1-5 years ago, and within the last year (see Appendix Table 2.2).

Amongst 18 to 39 year-olds, all respondents had type 1 diabetes. In the 40-59 age group, 67% had type 1 and 33% had type 2 diabetes. Forty-three percent of 60-79 year-olds had type 1 diabetes and 57% had type 2.

In people aged 18-39 years, 62% had DED and no one had DME. In the age group 40-59 years, over half (56%) had DED and 11% had DME. Of those aged 60-79 years, 29% had DED and 57% had DME.

In the subgroup diagnosed with diabetes 6-10 years ago, 25% had DED and 25% had DME. For those diagnosed 11-15 years ago, three-quarters had DED and one-quarter had DME. For those diagnosed 21 years ago or longer, 64% had DED and 21% had DME.

While 47% of respondents reported that their diabetes was well controlled, there was over half of respondents (53%) who felt that this was not the case. For the subgroup of respondents who felt their diabetes was controlled, half had DED and 21% had DME and for the group where their condition was not well controlled, half had DED and 19% 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		30 (100.0%)	23 (76.7%)	7 (23.3%)	15 (50.0%)	6 (20.0%)
Gender	Male	12 (41.4%)	8 (66.7%)	4 (33.3%)	5 (41.7%)	5 (41.7%)
	Female	17 (58.6%)	14 (82.4%)	3 (17.6%)	10 (58.8%)	1 (5.9%)
	Total Missing	1	1	0	0	0
Age	18-39 yrs.	13 (43.3%)	13 (100.0%)	0 (0.0%)	8 (61.5%)	0 (0.0%)
	40-59 yrs.	9 (30.0%)	6 (66.7%)	3 (33.3%)	5 (55.6%)	1 (11.1%)
	60-79 yrs.	7 (23.3%)	3 (42.9%)	4 (57.1%)	2 (28.6%)	4 (57.1%)
	80 yrs. plus	1 (3.3%)	1 (100.0%)	0 (0.0%)	0 (0.0%)	1 (100.0%)
Time since diagnosis	Within the last year	1 (3.3%)	1 (100.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	1 - 5 yrs.	1 (3.3%)	0 (0.0%)	1 (100.0%)	1 (100.0%)	0 (0.0%)
	6 - 10 yrs.	4 (13.3%)	2 (50.0%)	2 (50.0%)	1 (25.0%)	1 (25.0%)
	11 - 15 yrs.	4 (13.3%)	1 (25.0%)	3 (75.0%)	3 (75.0%)	1 (25.0%)
	16 - 20 yrs.	6 (20.0%)	6 (100.0%)	0 (0.0%)	1 (16.7%)	1 (16.7%)
	21 yrs. plus	14 (46.7%)	13 (92.9%)	1 (7.1%)	9 (64.3%)	3 (21.4%)
Control of Diabetes	Controlled	14 (46.7%)	12 (85.7%)	2 (14.3%)	7 (50.0%)	3 (21.4%)
	Not controlled	16 (53.3%)	11 (68.8%)	5 (31.3%)	8 (50.0%)	3 (18.8%)

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**

All of those surveyed saw a health care professional for their diabetes, with 93% seeing a diabetes specialist (on average 2.7 times per year) and 7% seeing a general or family doctor (see Appendix Table 2.3.1 and 2.3.2).

People were informed about their condition through a variety of channels. Most (83%) viewed information from a doctor or nurse as the primary source followed by the internet (47%) and 30% from a diabetes organisation or other health organisation. Other sources of information included radio and print media (23%) and nutritionist and dietician (20%) (see Table 2 and Appendix Table 2.4).

Table 2: Source of information regarding diabetes

Information Source	All Respondents (n=30)
Doctor or nurse	25 (83.3%)
Internet	14 (46.7%)
Diabetes organisation or other health organisation	9 (30.0%)
TV/Radio/Newspaper/Magazines	7 (23.3%)
Nutritionist or dietician	6 (20.0%)
Family/Friends/Neighbours	5 (16.7%)
Social media (e.g. Facebook, Twitter, blogs)	3 (10.0%)
Health educator	1 (3.3%)
Pharmacist	1 (3.3%)
None of the above	2 (6.7%)

A range of strategies was used by respondents to manage their diabetes. For those with type 1 diabetes, apart from insulin, 65% managed their diabetes with diet, 57% with exercise and 13% with natural or herbal medicine. Of the respondents with type 2 diabetes, 71% managed their condition with insulin, 43% with diet, 43% with oral medicine, and 14% with exercise.

Very few (7%) respondents were enrolled in diabetes management programmes and of these 50% 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 eye checks. For those who had eye checks (89%) these occurred at less than 6 months (73%), 6 - 12 months (12%), and greater than 12 months (3.8%) (see Appendix Table 2.7).

The main challenges in controlling diabetes cited by respondents were: the cost of care was high (59%), it was too hard to eat the right things (52%), long wait times for appointments to see their doctor or specialist (38%), the health services which were needed were not available (24%), and they did not want to think about having diabetes (24%) (see Appendix Table 2.9).

Support from family or friends (66%), free or low cost medicines or monitoring materials (41%), health education and information (28%), and to a much lesser extent, support groups and coordination of healthcare and services by a professional (3.4%) were viewed as important to improving the management of their diabetes (see Appendix Table 2.10).



## Nature and Information about Complications

Most (96%) respondents were aware of vision loss and believed other complications, such as: neuropathy (86%), foot ulcers (68%), amputation (64%), and kidney disease (64%) were associated with diabetes (see Appendix Table 2.11).

Patients were most concerned about vision loss (50%), amputation (25%), neuropathy (11%), foot ulcers (3.6%), and kidney disease (3.6%) (see Appendix Table 2.12).

Only 10% of respondents reported no complications with their diabetes. Neuropathy (59%), vision loss (45%), foot ulcers (17%), kidney disease (17%), and cardiovascular disease or stroke (17%) were the most commonly experienced complications (see Figure 1 and Appendix Table 2.13).

Aside from vision loss, there was a considerable increase in the frequency of people with DED and DME experiencing some complications compared to those without DED. The frequency of neuropathy increased from 38% in those without DED to 73% in DED and 50% in DME, as with the reporting of cardiovascular disease increasing from 0% for those without DED to 27% with DED and to 17% with DME (see Table 3 and Appendix EXP 1).

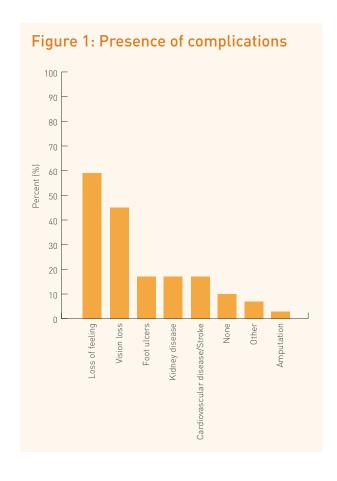


Table 3: Presence of complications without DED, with DED or DME

Complication	Without DED (n=8)	With DED (n=15)	With DME (n=6)
Any	5 (62.5%)	15 (100.0%)	6 (100.0%)
Loss of feeling in hands or toes (neuropathy)	3 (37.5%)	11 (73.3%)	3 (50.0%)
Vision loss	0 (0.0%)	10 (66.7%)	3 (50.0%)
Cardiovascular disease/Stroke	0 (0.0%)	4 (26.7%)	1 (16.7%)
Foot ulcers	1 (12.5%)	3 (20.0%)	1 (16.7%)
Kidney disease	1 (12.5%)	1 (6.7%)	3 (50.0%)
Amputation	0 (0.0%)	0 (0.0%)	1 (16.7%)
Other	0 (0.0%)	0 (0.0%)	2 (33.3%)
None	3 (37.5%)	0 (0.0%)	0 (0.0%)

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

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

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

 $\ensuremath{\mathsf{NB}}$  [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

The majority (90%) of respondents discussed complications with their health care professionals. Notwithstanding this nearly one in every three (31%) either never discussed eye complications (7%) or discussions only took place once symptoms arose (24%). The frequency of regular discussions varied from every visit (24%), multiple times a year (17%), and once a year (24%) (see Appendix Table 2.14).

Nearly all patients (93%) did what they could to prevent vision problems (e.g. having routine screenings and visiting specialists), yet 11% thought that vision problems were a normal part of ageing and 4% made no special effort to have a preventative approach to their eye health (see Appendix Table 2.15).

Eighty-six percent of respondents had received information about DR and DME with the doctor or nurse being the most common source (62%) following by 31% who viewed the internet as an important resource (see Table 4 and Appendix Table 3.9).

Table 4: Source of information about DR and DME

Source	All respondents (n=29)
Doctor/Nurse	18 (62.1%)
Internet	9 (31.0%)
Diabetes organisation or other health organisation	4 (13.8%)
TV/Radio/Newspaper/ Magazines	4 (13.8%)
Family/Friends/Neighbours	3 (10.3%)
None of the above	4 (13.8%)

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



## Screening for Diabetic Eye Disease

Most (97%) respondents reported having an eye exam for DED, with 86% within the last year and a further 11% more than one year ago but less than two years ago. Only 17% were aware of government sponsored screening programmes for DED (see Appendix Table 3.1 and Table 3.2).

While 93% thought they should have their eyes examined for DED every year there were varied smaller numbers of respondents who thought that it should happen every two years (see Appendix Table 3.4).

The biggest barriers to eye exams was the complicated and lengthy referral process (41%), long wait times on the day of the visit (31%), and eye exams not being available near their homes (28%) (see Table 5 and Appendix Table 3.5).

Table 5: Barriers to eye examinations

Identified Barriers	All Respondents (n=29)
Referral process is complicated or takes too long	12 (41.4%)
Long wait time on the day of the visit	9 (31.0%)
Eye exams are not available near my home	8 (27.6%)
Long wait time for appointment	7 (24.1%)
They are expensive	5 (17.2%)
Limited access to diabetes specialists	5 (17.2%)
Recommended treatments for eye problems are not available	4 (13.8%)
Fear of treatment/results	3 (10.3%)
Don't know much about my condition	1 (3.4%)
Burden on my family/friends	1 (3.4%)
Too many other things to do or worry about	1 (3.4%)
Clinics are too small or lack necessary equipment/staff	1 (3.4%)
Other	2 (6.9%)

#### 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, 92% had received laser treatment and 23% (n=3) received surgery. Almost one-quarter had completed treatment and 62% were still receiving treatment. Seventy-three percent felt that treatment had been successful and their vision either improved (27%) or stayed the same (46%) (see Table 6).

For the two respondents (13%) with DED who had not received treatment, the reason reported was the doctor did not recommend any treatment.

Eighty-three percent of patients with DME (n=5) had received treatment, with all receiving laser treatment and 40% also receiving anti-VEGF therapy and/or surgery, and most felt that the treatment had been successful and their vision had either improved (20%) or stayed the same (80%).

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

Table 6: Treatment characteristics of patients with DED and DME

	With DED and		
Question	Response	With DED (n=15)	With DME (n=6)
Have you	Yes	13 (86.7%)	5 (83.3%)
had any treatment for diabetic eye disease?	No	2 (13.3%)	1 (16.7%)
What	Laser	12 (92.3%)	5 (100.0%)
treatment	Anti-VEGF	1 (7.7%)	2 (40.0%)
did you receive?	Surgery	3 (23.1%)	2 (40.0%)
	Other	1 (7.7%)	1 (20.0%)
Did you	Yes	3 (23.1%)	2 (40.0%)
complete	No	2 (15.4%)	0 (0.0%)
the treatment?	Still receiving treatment	8 (61.5%)	3 (60.0%)
Do you feel that the	Yes, and vision improved	3 (27.3%)	1 (20.0%)
treatment worked?	Yes, but vision stayed the same	5 (45.5%)	4 (80.0%)
	Still waiting to know	1 (9.1%)	0 (0.0%)
	Don't know/ Not sure	2 (18.2%)	0 (0.0%)
What is/ are the reason(s) that you	Eye doctor was located too far away	1 (50.0%)	0 (0.0%)
did not complete the treatment?	Other	2 (100.0%)	0 (0.0%)
What are the reason(s) that you have not had treatment for diabetic eye disease?	My doctor did not recommend any treatment	2 (100.0%)	0 (0.0%)
	Treatment would not be effective	0 (0.0%)	1 (100.0%)

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

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

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

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



## Impact of Diabetic Eye Disease and Diabetic Macular Edema

Over half of those diagnosed with DED or DME said that their vision was affected (43% significantly, 52% slightly) (see Appendix Table 3.6).

Three-quarters of these respondents said that vision loss impacted employment opportunities and maintaining a job (35%), their ability to drive a vehicle (30%), be involved in leisure activities or exercise (25%), ability to manage their underlying diabetes (20%), travel (5%), and undertake household responsibilities, such as cooking or cleaning (5%) (see Table 7).

Table 7: Activities affected through vision impairment and loss

	All Respondents (n=20)
Work or keeping a job	7 (35.0%)
Driving (a car/vehicle)	6 (30.0%)
Leisure activities/exercise	5 (25.0%)
Managing my diabetes	4 (20.0%)
Travelling	1 (5.0%)
Household responsibilities, such as cooking or cleaning	1 (5.0%)
Other	4 (20.0%)
None	5 (25.0%)

Sixty percent of those with DED and 33% with DME were in paid employment compared with 50% without DED. Patients with vision complications reported difficulties with working or keeping a job (35%) and 13% of those with DED (n=2) were not working at all (see Table 8 and Appendix EXP 5.1).

One-third of those surveyed did not receive assistance from the government while 56% received some kind of pension. Eighty-three percent of those with DME and 69% with DED received assistance from the government compared with 50% of those without DED (see Appendix Table 4.5).

Sixty-two percent of respondents said they had no trouble paying for food at any time during the past year. Twenty-nine percent stated that their access to health care was affected because of the place they lived (see Appendix Table 4.6 and Table 4.7).

Sixty-one percent of respondents said they worried about their health, 11% about family and 11% were not worried about any of the items in the survey (see Appendix Table 4.8).

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

Question	Response	Without DED (n=8)	With DED (n=15)	With DME (n=6)
Are you currently working?	Working for pay	4 (50.0%)	9 (60.0%)	2 (33.3%)
	Volunteering	1 (12.5%)	0 (0.0%)	1 (16.7%)
	Retired	1 (12.5%)	3 (20.0%)	3 (50.0%)
	Student	1 (12.5%)	1 (6.7%)	0 (0.0%)
	Not working	1 (12.5%)	2 (13.3%)	0 (0.0%)
Question	Response	Without DED (n=8)	With DED (n=13)	With DME (n=6)
Do you receive assistance from the government?	Income assistance	1 (12.5%)	1 (7.7%)	1 (16.7%)
	Medical assistance	0 (0.0%)	5 (38.5%)	1 (16.7%)
	Housing assistance	0 (0.0%)	0 (0.0%)	1 (16.7%)
	Pension assistance	4 (50.0%)	7 (53.8%)	4 (66.7%)
	None of the above	4 (50.0%)	4 (30.8%)	1 (16.7%)
Question	Response	Without DED (n=8)	With DED (n=15)	With DME (n=6)
Did you have trouble paying for food at anytime during the past year?	Yes	2 (25.0%)	7 (46.7%)	2 (33.3%)
	No	6 (75.0%)	8 (53.3%)	4 (66.7%)

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

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

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

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

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



#### **Self-reported Quality of Life**

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

Sixty percent of people with DED, 29% without DED and 80% with DME reported that their health was poor. An unusual finding in self-reported quality of life was that there was a marked increased proportion (55%) of those without DED compared to those with DED reporting days where their activity was limited.

Compared with 14% of those without DED, 40% of people with DED and 50% of people with DME 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 hypertension or high blood pressure.

Compared to those without DED, people living with DED and DME were more limited by impairments, including vision and heart problems. Of note, were potential mobility challenges manifested through back and neck problems, vision problems and hypertension or high blood pressure. These patients have complex comorbidities that require careful management across the health and social care system (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	5 (71.4%)	6 (40.0%)	1 (20.0%)
Self-rated health: Poor	2 (28.6%)	9 (60.0%)	4 (80.0%)
Physically unhealthy days	5 (83.3%)	5 (83.3%)	1 (50.0%)
Mentally unhealthy days	3 (50.0%)	2 (33.3%)	1 (50.0%)
Unhealthy days	5 (83.3%)	5 (83.3%)	1 (50.0%)
Activity limitation days	4 (80.0%)	2 (25.0%)	0 (0.0%)

 $<sup>\</sup>label{eq:NB} NB~\cite{MBDD} = respondents~who~did~not~select~\cite{MBDDD} and~\cite{DMEDDDD}.$ 

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.

# Bulgaria DR Barometer Findings:

#### **Health Care Professionals**

#### **Key Demographic Characteristics**

There were ten health care professionals who answered at least one of the survey questions in Bulgaria. Of these, one was a diabetes specialist (10%) and seven were ophthalmologists (70%). The remaining respondents were other types of health care 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 11 years, with the ophthalmologist subgroup an average of 14 years (see Appendix PT 1.5).

Health care professionals were well educated (all had a graduate or advanced degree), 67% were female and 33% male and the largest proportions (33%) were aged between 30 - 39 years and 40-49 years (see Appendix PT 3.1 and Table 10).

Table 10: Summary of key characteristics of health care professionals

Group	Subgroup	All Respondents	Ophthalmologist
All respondents		10 (100.0%)	7 (70.0%)
Age group	30 - 39 yrs.	2 (33.3%)	2 (33.3%)
	40 - 49 yrs.	2 (33.3%)	2 (33.3%)
	50 - 59 yrs.	1 (16.7%)	1 (16.7%)
	70 - 79 yrs.	1 (16.7%)	1 (16.7%)
Gender	Female	4 (66.7%)	4 (66.7%)
	Male	2 (33.3%)	2 (33.3%)
Education	Graduate or advanced degree (e.g. PhD, MD, etc.)	6 (100.0%)	6 (100.0%)

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



#### Clinical Practice Characteristics

Thirty-three percent of all providers had their main practice setting in an eye clinic and for ophthalmologists only, the settings were eye clinic (43%) and hospital (43%). All health care professionals worked in an urban setting (see Appendix PT 2.1 and PT 2.2).

Most health care professionals worked in the private sector (56%) and ophthalmologists worked mainly in private (71%) and government sectors (14%) (see Appendix PT 2.3).

The health care professionals reported that 71% of patients split the cost between themselves and their insurance company, 57% pay through insurance for services and 29% pay out-of-pocket (full fees) for services. The pattern was similar for ophthalmologists, where 83% of patients split the cost between themselves and their insurance company, 67% pay through insurance for services and 33% pay out-of-pocket (full fees) for services (see Appendix PT 2.7).

On average, all providers saw 81 patients per week and 27% (on average) had diabetes. Similarly, ophthalmologists saw an average 92 patients per week and 28% had diabetes (see Appendix PT 2.6).

For all health care professionals, the average waiting time for an appointment was most commonly between one week and a month (71%) (see Appendix PT 2.5).

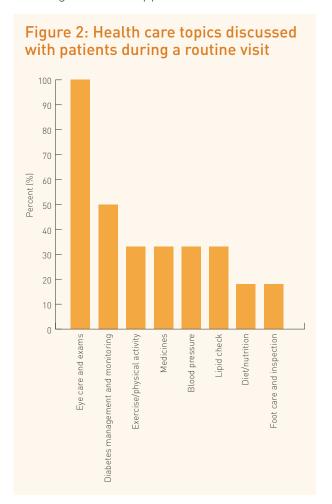
For an appointment with an ophthalmologist, it was usually between one week and a month in 83% of practices but for a further 17% the wait time was less than one week.

Table 11: Average wait times to schedule an appointment

Wait Time Intervals	All Respondents (n=7)	Ophthalmologist (n=6)
Less than 1 week	1 (14.3%)	1 (16.7%)
More than 1 week but less than 1 month	5 (71.4%)	5 (83.3%)
Six or more months	1 (14.3%)	0 (0.0%)

#### **Patient Education Information**

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



Health care professionals stated that written information about diabetes was available yet the adequacy of that which was related to eye complications varied. Half of all providers, including ophthalmologists, had sufficient information about eye complications yet half had no written information available for their patients (see Table 12 and Appendix PT 2.11).



#### **Guidelines and Protocols**

Only thirty-three percent of providers, including ophthalmologists, had written protocols for the management of diabetes, which were used by staff. However, 67% had no protocols (see Appendix PT 2.12).

With respect to the management of diabetes-related vision issues, 50% of health care professionals, including ophthalmologists, had written protocols and they were used by staff. Consistent with previous findings one in three providers did not have protocols on the management of diabetes-related vision issues available (see Table 12 and Appendix PT 2.13).

Table 12: Availability and use of information and protocols

Question	Response	All Respondents (n=6)	Ophthalmologist (n=6)
Is there written information about diabetes available	Yes, and information on eye complications is sufficient	3 (50.0%)	3 (50.0%)
for patients in your main practice?	No written information is available for patients	3 (50.0%)	3 (50.0%)
Question	Response	All Respondents (n=6)	Ophthalmologist (n=6)
Do you have written protocols/guidelines for	Yes, available and used by staff	3 (50.0%)	3 (50.0%)
detection and management of diabetes-related vision issue available in your main practice?	Not available	2 (33.3%)	2 (33.3%)
	Don't know/Not sure	1 [16.7%]	1 (16.7%)

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

### Screening Protocols and Barriers in the Care Pathway

Timing for the initial eye exam for persons with diabetes varied depending upon the type of diabetes. For those with type 1 diabetes, half of the providers reported that the initial eye exam should occur at time of the diagnosis of diabetes and for those with type 2 diabetes, 83% of providers recommended an eye exam at time of diagnosis (see Appendix PT 2.14).

Overall, all health care professionals reported that follow-up eye examinations should be conducted every year and all health care professionals screen patients for DR (see Appendix PT 2.15 and PT 2.16).

Across all health care professionals, 17% send appointment reminders for general follow-up appointments and 83% do not. Only 50% shared information to optimise patient care management (see Appendix PT 2.19 and PT 2.20).

The most common patient characteristics influencing the referral process for eye complications were: diabetes duration (83%), high glucose levels (83%), presence of comorbidities such as hypertension (67%), patient's age (33%), and patient education level (33%) (see Appendix PT 2.17).

The major barriers to optimising eye health faced by patients with diabetes as reported by health care professionals were the referral process (67%), a lack of knowledge and/or awareness (67%) and the patient's fear of the treatment and/or results (67%) (see Table 13 and Appendix PT 2.18).



Table 13: Major barriers to optimising eye health

Response	All Respondents (n=6)	Ophthalmologists (n=6)
Referral process	4 (66.7%)	4 (66.7%)
Lack of knowledge and/or awareness	4 (66.7%)	4 (66.7%)
Patients fear of treatment/results	4 (66.7%)	4 (66.7%)
Limited access to eye specialists	3 (50.0%)	3 (50.0%)
Patients feel eye complications are unlikely	3 (50.0%)	3 (50.0%)
Patients feel eye exams are not important	3 (50.0%)	3 (50.0%)
Proximity to care	2 (33.3%)	2 (33.3%)
Limited access to diabetes specialists	2 (33.3%)	2 (33.3%)
Cost of care	1 (16.7%)	1 (16.7%)
Recommended treatments are not available	1 (16.7%)	1 (16.7%)
Patients feel they are a burden on family/friends	1 (16.7%)	1 (16.7%)
Patients have competing responsibilities and priorities	1 (16.7%)	1 (16.7%)

# Bulgaria DR Barometer Findings:

#### **Ophthalmologists**

There were six ophthalmologists who answered at least one of the supplementary questions (see Appendix PT 4.1 to PT 4.14). On average, 19% of patients seen by the ophthalmologists had DR and 13% DME (see Appendix PT 4.1 and PT 4.2).

#### Screening

The most common waiting time for a screening appointment for DED was between one week and a month (50%) with 33% stated it was less than 1 week (see Appendix PT 4.3). Sixty-seven percent reported a wait time from screening to diagnosis of less than 1 week and two ophthalmologists reported that a diagnosis was given at screening (see Appendix PT 4.4).

#### **Treatment and Challenges**

All ophthalmologists personally administer treatment for DR. The most common factors influencing how ophthalmologists treat patients with DR or DME were: presence of comorbidities such as hypertension (83%), duration of diabetes (67%), and high glucose levels (67%) (see Appendix PT 4.6 and PT 4.7).

The most common outreach venue for screening for DED was vision centres (50%) (see Appendix PT 4.13).

All ophthalmologists screen patients for DR based on fundoscopy through dilated pupils, optical coherence tomography, and fluorescein angiography. Additionally, 50% use retinal photo(s). All ophthalmologists treat DR and DME based on both visual and anatomical outcomes (see Appendix PT 4.8 and PT 4.9).

All ophthalmologists (n=6) reported that most patients present when visual problems have already occurred (see Appendix PT 4.10).

Eighty-three percent of ophthalmologists had received specific training on the treatment and diagnosis of DR and or DME. Sixty percent had training within the past year and 40% between one and five years ago. All ophthalmologists would be interested in online education and certification on DME, angiogenesis and anti-VEGF therapies (see Appendix PT 4.11 and PT 4.12).

Ophthalmologists said that the greatest challenge for improving patient outcomes in DED was a late diagnosis, complicated referral pathways, limited access to patient education and poor multi-disciplinary integration (see Table 14 and Appendix PT 4.14).



Table 14: Challenges for improving outcomes in DED

Question	Response	Ophthalmologist (n=6)
What do you perceive to be the	Late diagnosis	6 (100.0%)
greatest challenges for improving patient outcomes in diabetic eye	Referral pathways	5 (83.3%)
disease?	Limited access to patient education on diabetic retinopathy and diabetic macular edema	5 (83.3%)
	Multi-disciplinary team integration is poor	5 (83.3%)
	Government/insurance not able to cover patient costs	4 (66.7%)
	Reimbursement/restrictions on approved therapy	3 (50.0%)
	Ineffective screening services	3 (50.0%)
	No universal guidelines on referral/ screening	2 (33.3%)
	No universal guidelines on how to treat	1 (16.7%)
	No universal guideline on when to treat	1 (16.7%)
	Current available therapies not effective	1 (16.7%)

# Bulgaria DR Barometer Summary

In Bulgaria, 30 adults with diabetes and 10 health care professionals provided insights about their experiences of living with, managing and treating diabetes, DR and DME. The results of the DR Barometer Study, Bulgaria aim to help improve the level of awareness around diabetes and eye complications, and access and barriers to diabetes management, including screening and timely treatment for those diagnosed with DED and DME.

Bulgaria is the sixteenth most populous country in the European Union with a population just over 7 million. One of the major influences in the region is that of population ageing, which has serious policy and programme implications alongside the increased prevalence of many noncommunicable diseases. By 2050, 29% of the total population in Bulgaria will be aged 65 years and older.

Alongside the demographic changes, the prevalence of people with diabetes is climbing rapidly. Today, Bulgaria has over 459, 200 people living with diabetes, 7,014 deaths were attributed to diabetes (2015) and there are some 199,000 undiagnosed cases.

Health professionals, such as the doctor or nurse, most commonly informed patients about their condition. Diabetes and other health organisations and print and radio were also viewed as valuable sources of information. A trend globally, which was reflected in the Bulgaria study, was the increasing use of the internet by 47% of the respondents.

Only 7% of respondents were enrolled in a diabetes management programme and of these only 50% said there was information in the programme about the importance of screening for eye complications. While the proportion of respondents is extremely small, it may also be that diabetes management programmes are not easily available or accessible in Bulgaria.

Many respondents struggled with the basic management of their diabetic condition because of the high cost of care, it was too hard to eat the right things, and there were long wait times for appointments. For others surveyed, the health services that were needed were not available and they did not want to think about having diabetes.

There was a high awareness of the complications associated with diabetes including vision loss (96%). Vision loss was by far the most concerning followed by neuropathy and foot ulcers. Only ten percent of those surveyed had no complications with their diabetes and all with DED and DME had additional complications.

Knowing that diabetic-related vision loss is preventable, addressing barriers to eye screening is an important policy issue. Most (97%) respondents had received an eye exam, which is understandable considering the purposeful sample however, there remained many barriers including the complicated and lengthy referral process, long wait times on the day of the appointment, and eye exams not being available near the respondent's home.



Evidence shows that the relationship between the patient and the health care professional is critical to ensure realistic and optimal patient outcomes. It was therefore surprising that 31% of those surveyed had either never had a conversation about eye complications with their health professional or it only took place only once symptoms were present. Equally concerning is the myths and perceptions around vision changes with 11% reporting that vision problems were a normal part of ageing and some respondents not making any special effort to prevent vision problems.

Most people diagnosed with DED or DME said that their vision was slightly or significantly affected which in turn affected their health, lifestyle, and life choices with many experiencing difficulty in working or keeping a job, driving a vehicle, managing their underlying diabetes, and being involved in leisure activities or exercise.

Respondents with DME said that they preferred a proactive approach to prevent further vision loss rather than only receiving treatment when their vision deteriorates. Health and family were the top 'worries' on the minds of the respondents surveyed.

Patient education is very much at the heart of a proactive approach. That being said, it was unexpected and concerning that only half of the ophthalmologist group had written information about diabetes and potential eye complications and half said there was no written information available.

Furthermore, half of all providers (including ophthalmologists) did not have protocols on the management of diabetes-related vision issues available.

Recommendations for the timing of the initial eye exam for persons with diabetes varied depending upon the type of diabetes and the provider. For patients with type 1 diabetes half of the providers recommended an exam at the time of diagnosis and 84% for those with type 2 diabetes.

Certain factors influenced the referral process for respondents, the main being, diabetes duration, high glucose levels, the presence of comorbidities such as hypertension, and the patient's age.

The greatest challenges for improving patient outcomes with DED as perceived by all ophthalmologist was a late diagnosis and 83% said that the greatest challenge was that multi-disciplinary team integration was poor.

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

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

# 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%20 and%20projections
- <sup>2</sup> International Diabetes Federation. (2015). *IDF Diabetes Atlas*. Accessed from: http://www.diabetesatlas.org/

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

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

Table 1.1

Survey Information	Number of Respondents (%)	
All valid respondents [1]	33 (100.0%)	
Respondents aged 18 or over	33 (100.0%)	
Respondents with diabetes	30 (90.9%)	

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

Table 1.2

Survey Information	Number of Respondents (%)
All valid respondents	33 (100.0%)
Included in Diabetic Analysis Set	30 (90.9%)
Excluded from Diabetic Analysis Set	3 (9.1%)
Reasons for exclusion from diabetic analysis set	•
Not diagnosed with diabetes	3

Table 1.3

Survey Information	Number of Respondents (%)
Diabetic Analysis Set	30 (100.0%)
World Bank Income Group: Upper-middle income	30 (100.0%)
Persons with diabetic eye disease (DED)	15 (50.0%)
Persons with diabetic macular edema (DME)	6 (20.0%)
Persons with Type I diabetes	23 (76.7%)
Persons with Type II diabetes	7 (23.3%)
Persons seeing health care professional for diabetes	30 (100.0%)
Persons with eye disease & not received treatment	3 (10.0%)
Persons with eye disease & received treatment	18 (60.0%)

Table 2.1



Question	Response	Number of Respondents (%)
With which type of diabetes have you been diagnosed?	Туре І	23 (76.7)
	Type II	7 (23.3)
	Total Valid Response	30 (100.0)

Question	Response	Number of Respondents (%)
When was your diabetes diagnosed?	Within the last year	1 (3.3)
	1 - 5 years ago	1 (3.3)
	6 - 10 years ago	4 (13.3)
	11 - 15 years ago	4 (13.3)
	16 - 20 years ago	6 (20.0)
	21 years ago or longer	14 (46.7)
	Total Valid Response	30 (100.0)

#### **Table 2.3.1**

Question	Response	Number of Respondents (%)
Do you see a health care professional for your diabetes?	Yes	30 (100.0)
	Total Valid Response	30 (100.0)
What kind of health care professional?	General/Family Doctor	2 (6.7)
	Diabetes Specialist	28 (93.3)
	Total Valid Response	30 (100.0)

#### **Table 2.3.2**

Type of health care professional	Times per year seen for diabetes	Value
General/Family Doctor	Total valid numeric response (n)	0
	Mean	
	SD	
	Median	
	Min	

Type of health care professional	Times per year seen for diabetes	Value
	Max	
	Don't know/Not sure	1
	Total missing	1
Diabetes Specialist	Total valid numeric response (n)	23
	Mean	2.7
	SD	1.1
	Median	2.0
	Min	1
	Max	6
	Don't know/Not sure	1
	Total missing	4

Question	Response	Number of Respondents (%)
How have you received information about diabetes?	Doctor or nurse	25 (83.3%)
	Health educator	1 (3.3%)
	Nutritionist or dietitian	6 (20.0%)
	Diabetes organization or other health organization	9 (30.0%)
	Family/Friends/Neighbors	5 (16.7%)
	TV/Radio/Newspaper/Magazines	7 (23.3%)
	Internet	14 (46.7%)
	Social media (e.g. Facebook, Twitter, blogs)	3 (10.0%)
	Pharmacist	1 (3.3%)
	None of the above	2 (6.7%)
	Total Valid Response	30 (100.0%)

Table 2.5

Question	Response	Number of Respondents (%)
How do you manage your diabetes?	Diet	18 (60.0%)
	Oral medicine	5 (16.7%)



Question	Response	Number of Respondents (%)
	Exercise	14 (46.7%)
	Insulin	28 (93.3%)
	Natural/Herbal medicine	3 (10.0%)
	Total Valid Response	30 (100.0%)

Question	Response	Number of Respondents (%)
Are you currently enrolled in a diabetes patient management support programme?	Yes	2 (6.7)
	No	28 (93.3)
	Total Valid Response	30 (100.0)
Who sponsors the programme?	Hospital support program	1 (50.0)
	Patient organization support program	1 (50.0)
	Total Valid Response	2 (100.0)
	Total missing	28
Does the programme include education on the importance of screening for diabetic eye complications?	Yes	1 (50.0)
	No	1 (50.0)
	Total Valid Response	2 (100.0)
	Total missing	28

Test	Response	Number of Respondents (%)
Have you ever had the following tests in a doctor's office or clinic?		
Blood glucose test	Yes	29 (100.0%)
	Less than 6 months	26 (89.7%)
	6 - 12 months	3 (10.3%)
	Total valid response	29 (100.0%)
	Total missing	1
	Total valid response	29 (100.0%)

Test	Response	Number of Respondents (%)
	Total missing	1
Urine check	Yes	28 (96.6%)
	Less than 6 months	23 (79.3%)
	6 - 12 months	4 (13.8%)
	Greater than 12 months	1 (3.4%)
	Total valid response	28 (96.6%)
	Total missing	2
	No	1 (3.4%)
	Total valid response	29 (100.0%)
	Total missing	1
Weight check	Yes	25 (89.3%)
	Less than 6 months	19 (67.9%)
	6 - 12 months	4 (14.3%)
	Greater than 12 months	1 (3.6%)
	Total valid response	24 (85.7%)
	Total missing	6
	No	3 (10.7%)
	Total valid response	28 (100.0%)
	Total missing	2
Blood pressure check	Yes	28 (96.6%)
	Less than 6 months	23 (79.3%)
	6 - 12 months	3 (10.3%)
	Greater than 12 months	1 (3.4%)
	Total valid response	27 (93.1%)
	Total missing	3
	No	1 (3.4%)
	Total valid response	29 (100.0%)
	Total missing	1
Foot check	Yes	19 (67.9%)
	Less than 6 months	13 (46.4%)
	6 - 12 months	6 (21.4%)



Test	Response	Number of Respondents (%)
	Total valid response	19 (67.9%)
	Total missing	11
	No	9 (32.1%)
	Total valid response	28 (100.0%)
	Total missing	2
Eye check	Yes	23 (88.5%)
	Less than 6 months	19 (73.1%)
	6 - 12 months	3 (11.5%)
	Greater than 12 months	1 (3.8%)
	Total valid response	23 (88.5%)
	Total missing	7
	No	3 (11.5%)
	Total valid response	26 (100.0%)
	Total missing	4

Question	Response	Number of Respondents (%)
How well do you think your diabetes is controlled?	Very well	1 (3.3%)
	Well	13 (43.3%)
	Not very well	6 (20.0%)
	Not well at all	10 (33.3%)
	Total Valid Response	30 (100.0%)

Question	Response	Number of Respondents (%)
What are the main challenges you face in controlling your diabetes?	High cost of care	17 (58.6%)
	Travel to my regular doctor or specialist is difficult	2 (6.9%)
	Long wait time for an appointment to	11 (37.9%)

Question	Response	Number of Respondents (%)
	see my doctor or specialist	
	Health services needed are not available	7 (24.1%)
	Don't know enough about diabetes	2 (6.9%)
	Too hard to eat the right things	15 (51.7%)
	Too many other things to do	6 (20.7%)
	Stigma or discrimination because of diabetes	1 (3.4%)
	Don't want to think about having diabetes	7 (24.1%)
	Other	3 (10.3%)
	Total Valid Response	29 (100.0%)
	Total missing	1

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	12 (41.4%)
	Support groups	1 (3.4%)
	Support from family or friends	19 (65.5%)
	Health education and information	8 (27.6%)
	Coordination of healthcare and services by a professional	1 (3.4%)
	Other	1 (3.4%)
	None	5 (17.2%)
	Total Valid Response	29 (100.0%)
	Total missing	1

Question	Response	Number of Respondents (%)
What complications (or problems), to your knowledge, arise from diabetes?	Amputation	18 (64.3%)
	Foot ulcers	19 (67.9%)



Question	Response	Number of Respondents (%)
	Increased risk of broken bones or fractures	6 (21.4%)
	Loss of feeling in hands or toes (neuropathy)	24 (85.7%)
	Vision loss	27 (96.4%)
	Irritable bowel disease	6 (21.4%)
	Kidney disease	18 (64.3%)
	Cardiovascular disease/Stroke	17 (60.7%)
	Other	4 (14.3%)
	Total Valid Response	28 (100.0%)
	Total missing	2

### **Table 2.12**

Question	Response	Number of Respondents (%)
Which complication of diabetes are you most concerned about?	Amputation	7 (25.0)
	Foot ulcers	1 (3.6)
	Loss of feeling in hands or toes (neuropathy)	3 (10.7)
	Vision loss	14 (50.0)
	Kidney disease	1 (3.6)
	Other	1 (3.6)
	Don't know/Not sure	1 (3.6)
	Total Valid Response	28 (100.0)
	Total missing	2

### **Table 2.13**

Question	Response	Number of Respondents (%)
Which of the following complications of diabetes do you have?	Amputation	1 (3.4%)
	Foot ulcers	5 (17.2%)
	Broken bones or fractures	2 (6.9%)

Question	Response	Number of Respondents (%)
	Loss of feeling in hands or toes (neuropathy)	17 (58.6%)
	Vision loss	13 (44.8%)
	Irritable bowel disease	2 (6.9%)
	Kidney disease	5 (17.2%)
	Cardiovascular disease/Stroke	5 (17.2%)
	Other	2 (6.9%)
	Don't know/Not sure	2 (6.9%)
	None	3 (10.3%)
	Total Valid Response	29 (100.0%)
	Total missing	1

## **Table 2.14**

Question	Response	Number of Respondents (%)
How often do you discuss the possibility of eye complications with your health care professional?	Every visit	7 (24.1%)
	Multiple times per year	5 (17.2%)
	Once per year	7 (24.1%)
	Only when symptoms arise	7 (24.1%)
	Never	2 (6.9%)
	Don't know/Not sure	1 (3.4%)
	Total Valid Response	29 (100.0%)
	Total missing	1

## **Table 2.15**

Question	Response	Number of Respondents (%)
Which of the following best describes your attitude to vision issues?	I think that vision problems are a normal part of ageing	3 (10.7%)
	I do what I can to prevent vision problems (e.g. get routine screenings, visit	26 (92.9%)



Question	Response	Number of Respondents (%)
	specialists)	
	I do not make any special effort to prevent vision problems	1 (3.6%)
	Total Valid Response	28 (100.0%)
	Total missing	2

#### **Table 2.16**

Question	Response	Number of Respondents (%)
What type of health insurance do you have?	Public	23 (79.3)
	Public - Private	4 (13.8)
	Private	1 (3.4)
	None	1 (3.4)
	Total Valid Response	29 (100.0)
	Total missing	1

### **Table 2.17**

Question	Response	Number of Respondents (%)
Most often, how do you pay for the following types of medical care and services?		
General doctor visits (e.g. primary care doctor)	Care is free	15 (55.6)
	Insurance pays total cost	6 (22.2)
	Insurance and out-of- pocket/cash (e.g. co-pays)	5 (18.5)
	Do not use service	1 (3.7)
	Total Valid Response	27 (100.0)
	Total missing	3
Specialist medical visits (e.g. eye doctor, gynecologist, urologist)	Care is free	11 (39.3)
	Insurance pays total cost	6 (21.4)
	Insurance and out-of- pocket/cash (e.g. co-pays)	10 (35.7)
	Out-of-pocket only (pay cash for all care)	1 (3.6)
	Total Valid Response	28 (100.0)

Question	Response	Number of Respondents (%)
	Total missing	2
Medicines	Care is free	5 (19.2)
	Insurance pays total cost	3 (11.5)
	Insurance and out-of- pocket/cash (e.g. co-pays)	15 (57.7)
	Out-of-pocket only (pay cash for all care)	2 (7.7)
	Do not use service	1 (3.8)
	Total Valid Response	26 (100.0)
	Total missing	4
Medical supplies (e.g. blood glucose meter/strips)	Care is free	11 (40.7)
	Insurance pays total cost	4 (14.8)
	Insurance and out-of- pocket/cash (e.g. co-pays)	11 (40.7)
	Out-of-pocket only (pay cash for all care)	1 (3.7)
	Total Valid Response	27 (100.0)
	Total missing	3
Procedures	Care is free	7 (25.9)
	Insurance pays total cost	6 (22.2)
	Insurance and out-of- pocket/cash (e.g. co-pays)	10 (37.0)
	Out-of-pocket only (pay cash for all care)	1 (3.7)
	Do not use service	2 (7.4)
	Don't know/Not Sure	1 (3.7)
	Total Valid Response	27 (100.0)
	Total missing	3
Tests/screenings	Care is free	10 (35.7)
	Insurance pays total cost	3 (10.7)
	Insurance and out-of- pocket/cash (e.g. co-pays)	9 (32.1)
	Out-of-pocket only (pay cash for all care)	4 (14.3)
	Do not use service	1 (3.6)



Question	Response	Number of Respondents (%)
	Don't know/Not Sure	1 (3.6)
	Total Valid Response	28 (100.0)
	Total missing	2
Health education	Care is free	5 (18.5)
	Insurance pays total cost	4 (14.8)
	Insurance and out-of- pocket/cash (e.g. co-pays)	1 (3.7)
	Out-of-pocket only (pay cash for all care)	3 (11.1)
	Do not use service	14 (51.9)
	Total Valid Response	27 (100.0)
	Total missing	3
Counseling	Care is free	8 (29.6)
	Insurance pays total cost	5 (18.5)
	Insurance and out-of- pocket/cash (e.g. co-pays)	2 (7.4)
	Out-of-pocket only (pay cash for all care)	4 (14.8)
	Do not use service	7 (25.9)
	Don't know/Not Sure	1 (3.7)
	Total Valid Response	27 (100.0)
	Total missing	3

Question	Response	Number of Respondents (%)
Are you aware of any government sponsored screening programs for diabetic eye disease (diabetic retinopathy)?	Yes	5 (17.2%)
	No	24 (82.8%)
	Total valid response	29 (100.0%)
	Total missing	1

Question	Response	Number of Respondents (%)
Have you ever had an eye exam for diabetic eye disease?	Yes	28 (96.6%)
	No	1 (3.4%)
	Total valid response	29 (100.0%)
	Total missing	1
How long ago was your last eye exam?	Within the last year	24 (85.7%)
	More than 1 year ago but less than 2 years	3 (10.7%)
	More than 3 years ago but less than 5 years	1 (3.6%)
	Total valid response	28 (100.0%)
	Total missing	2
Who did the last exam?	Eye doctor/Eye clinic	28 (100.0%)
	Total valid response	28 (100.0%)
	Total missing	2

Question	Response	Number of Respondents (%)
Have you ever had a dilated eye exam, where your eyes are examined after eye drops?	Yes	27 (96.4%)
	No	1 (3.6%)
	Total valid response	28 (100.0%)
	Total missing	2

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	27 (93.1%)
	Less often than every two years	1 (3.4%)
	Don't know/Not sure	1 (3.4%)
	Total valid response	29 (100.0%)



Question	Response	Number of Respondents (%)
	Total missing	1

Question	Response	Number of Respondents (%)
For you, what are the biggest barriers to eye exams?	They are expensive	5 (17.2%)
	Eye exams are not available near my home	8 (27.6%)
	Long wait time for appointment	7 (24.1%)
	Long wait time on the day of the visit	9 (31.0%)
	Referral process is complicated or takes too long	12 (41.4%)
	Recommended treatments for eye problems are not available	4 (13.8%)
	Don't know much about my condition	1 (3.4%)
	Fear of treatment/results	3 (10.3%)
	Burden on my family/friends	1 (3.4%)
	Limited access to diabetes specialists	5 (17.2%)
	Too many other things to do or worry about	1 (3.4%)
	Clinics are too small or lack necessary equipment/staff	1 (3.4%)
	Other	2 (6.9%)
	Total valid response	29 (100.0%)
	Total missing	1

Question	Response	Number of Respondents (%)
Have you been diagnosed with diabetic eye disease?	Yes	21 (72.4%)
	No	8 (27.6%)
	Total valid response	29 (100.0%)
	Total missing	1
Has your diabetic eye disease affected	Yes, slightly	11 (52.4%)

Question	Response	Number of Respondents (%)
your vision?		
	Yes, significantly	9 (42.9%)
	No	1 (4.8%)
	Total valid response	21 (100.0%)
	Total missing	9
Have vision issues caused you to have difficulty with any of the following?	Traveling	1 (5.0%)
	Household responsibilities, such as cooking or cleaning	1 (5.0%)
	Leisure activities/exercise	5 (25.0%)
	Work or keeping a job	7 (35.0%)
	Managing my diabetes	4 (20.0%)
	Other	4 (20.0%)
	None	5 (25.0%)
	Driving (a car/vehicle)	6 (30.0%)
	Total valid response	20 (100.0%)
	Total missing	10

Table 3.7

Question	Response	Number of Respondents (%)
Have you had any treatment for diabetic eye disease?	Yes	18 (85.7%)
	No	3 (14.3%)
	Total valid response	21 (100.0%)
	Total missing	9
What treatment did you receive?	Laser	17 (94.4%)
	Injection in the eye (Anti- VEGF)	3 (16.7%)
	Surgery	5 (27.8%)
	Other	2 (11.1%)
	Total valid response	18 (100.0%)
	Total missing	12
Did you complete the treatment?	Yes	5 (27.8%)



Question	Response	Number of Respondents (%)
	No	2 (11.1%)
	Still receiving treatment	11 (61.1%)
	Total valid response	18 (100.0%)
	Total missing	12
Do you feel that the treatment worked?	Yes, and vision improved	4 (25.0%)
	Yes, but vision stayed the same	9 (56.3%)
	Still waiting to know	1 (6.3%)
	Don't know/Not sure	2 (12.5%)
	Total valid response	16 (100.0%)
	Total missing	14
What is/are the reason(s) that you did not complete the treatment?	Eye doctor was located too far away	1 (50.0%)
	Other	2 (100.0%)
	Total valid response	2 (100.0%)
	Total missing	28
What are the reason(s) that you have not had treatment for diabetic eye disease?	My doctor did not recommend any treatment	2 (66.7%)
	Treatment would not be effective	1 (33.3%)
	Total valid response	3 (100.0%)
	Total missing	27

Question	Response	Number of Respondents (%)
Have you been diagnosed with diabetic macular edema?	Yes	6 (20.7%)
	No	16 (55.2%)
	Don't know/Not sure	7 (24.1%)
	Total valid response	29 (100.0%)
	Total missing	1
If Yes, which of the following would you prefer	Treatment to prevent further vision loss	5 (100.0%)
	Total valid response	5 (100.0%)

Question	Response	Number of Respondents (%)
	Total missing	25

Question	Response	Number of Respondents (%)
Have you received information about diabetic retinopathy or diabetic macular edema from any of the following sources?	Doctor/Nurse	18 (62.1%)
	Diabetes organization or other health organization	4 (13.8%)
	Family/Friends/Neighbors	3 (10.3%)
	TV/Radio/Newspaper/Magazines	4 (13.8%)
	Internet	9 (31.0%)
	None of the above	4 (13.8%)
	Total valid response	29 (100.0%)
	Total missing	1

## Table 4.1

Question	Response	Number of Respondents (%)
What is your gender?	Female	17 (58.6)
	Male	12 (41.4)
	Total Valid Response	29 (100.0)
	Total missing	1
Please indicate your age	18 - 29	6 (20.0)
	30 - 39	7 (23.3)
	40 - 49	6 (20.0)
	50 - 59	3 (10.0)
	60 - 69	7 (23.3)
	80 - 89	1 (3.3)
	Total Valid Response	30 (100.0)

Table 4.2

Question Response	Number of Respondents (%)
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Question	Response	Number of Respondents (%)
Where do you live?	Urban setting	25 (86.2)
	Non-urban setting	4 (13.8)
	Total Valid Response	29 (100.0)
	Total missing	1

### Table 4.3

Question	Response	Number of Respondents (%)
What is the highest level of education you completed?	Primary school	1 (3.4)
	Secondary school	12 (41.4)
	College/University	2 (6.9)
	Graduate or post- graduate	14 (48.3)
	Total valid response	29 (100.0)
	Total missing	1

### Table 4.4

Question	Response	Number of Respondents (%)
Are you currently working?	Working for pay	15 (51.7)
	Volunteering	2 (6.9)
	Retired	7 (24.1)
	Student	2 (6.9)
	Not working	3 (10.3)
	Total Valid Response	29 (100.0)
	Total missing	1

### Table 4.5

Question	Response	Number of Respondents (%)
Do you receive assistance from the government?	Income assistance	3 (11.1%)
	Medical assistance	6 (22.2%)
	Housing assistance	1 (3.7%)
	Pension assistance	15 (55.6%)

Question	Response	Number of Respondents (%)
	None of the above	9 (33.3%)
	Total valid response	27 (100.0%)
	Total missing	3

### Table 4.6

Question	Response	Number of Respondents (%)
Did you have trouble paying for food at anytime during the past year?	Yes	11 (37.9)
	No	18 (62.1)
	Total Valid Response	29 (100.0)
	Total missing	1

### 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	3 (10.7)
	Income	6 (21.4)
	Place of birth	2 (7.1)
	Place where you live	8 (28.6)
	Race	1 (3.6)
	Religion	1 (3.6)
	Tribal affiliation	1 (3.6)
	None of the above	17 (60.7)
	Total valid response	28 (100.0)
	Total missing	2

### Table 4.8

Question	Response	Number of Respondents
		(%)



Question	Response	Number of Respondents (%)
Which of the following do you worry about most?	Food	1 (3.6)
	Housing	2 (7.1)
	Money	2 (7.1)
	Health	17 (60.7)
	Family	3 (10.7)
	None of the above	3 (10.7)
	Total Valid Response	28 (100.0)
	Total missing	2

### Table 5.1

Question	Response	Number of Respondents (%)
In general, would you say your health is:	Very good	3 (11.1%)
	Good	9 (33.3%)
	Total good health	12 (44.4%)
	Fair	12 (44.4%)
	Poor	3 (11.1%)
	Fair or poor health	15 (55.6%)
	Total valid response	27 (100.0%)
	Total missing	3

### Table 5.2

Question	Response	Number of Respondents (%)
How many days during last 30 days was your physical health not good	Any unhealthy days	11 (78.6%)
	1-5 unhealthy days	5 (35.7%)
	6-10 unhealthy days	4 (28.6%)
	11-20 unhealthy days	1 (7.1%)
	21-30 unhealthy days	1 (7.1%)

Question	Response	Number of Respondents (%)
	No unhealthy days	3 (21.4%)
	Total valid response	14 (100.0%)
	Total missing	16

## **Table 5.3.1**

Question	Response	Number of Respondents (%)
How many days during last 30 days was your mental health not good	Any unhealthy days	6 (42.9%)
	1-5 unhealthy days	4 (28.6%)
	21-30 unhealthy days	2 (14.3%)
	No unhealthy days	8 (57.1%)
	Total valid response	14 (100.0%)
	Total missing	16

### **Table 5.3.2**

Question	Response	Number of Respondents (%)
Unhealthy days (physically or mentally unhealthy, max 30)	Any unhealthy days	11 (78.6%)
	1-5 unhealthy days	3 (21.4%)
	6-10 unhealthy days	6 (42.9%)
	21-30 unhealthy days	2 (14.3%)
	No unhealthy days	3 (21.4%)
	Total valid response	14 (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	6 (46.2%)
	1-5 unhealthy days	4 (30.8%)
	6-10 unhealthy days	1 (7.7%)
	11-20 unhealthy days	1 (7.7%)
	No unhealthy days	7 (53.8%)
	Total valid response	13 (100.0%)
	Total missing	17

#### 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	10 (45.5%)
	No	12 (54.5%)
	Total valid response	22 (100.0%)
	Total missing	8
Which impairment or health problem, if any, limits your activities?		
a) Arthritis/rheumatism	No	7 (77.8%)
	Don't know/Not sure	2 (22.2%)
	Total valid response	9 (100.0%)
	Total missing	21
b) Back or neck problem	Yes	6 (54.5%)
	No	5 (45.5%)
	Total valid response	11 (100.0%)
	Total missing	19
c) Fractures, bone/joint injury	Yes	3 (27.3%)

	No Refused Total valid	7 (63.6%) 1 (9.1%)
	Total valid	1 (9.1%)
	response	11 (100.0%)
	Total missing	19
d) Walking problem	Yes	6 (60.0%)
	No	4 (40.0%)
	Total valid response	10 (100.0%)
	Total missing	20
e) Lung/breathing problem	Yes	3 (33.3%)
	No	6 (66.7%)
	Total valid response	9 (100.0%)
	Total missing	21
f) Hearing problem	Yes	2 (20.0%)
	No	7 (70.0%)
	Don't know/Not sure	1 (10.0%)
	Total valid response	10 (100.0%)
	Total missing	20
g) Eye/vision problem	Yes	11 (91.7%)
	No	1 (8.3%)
	Total valid response	12 (100.0%)
	Total missing	18
h) Heart problem	Yes	7 (58.3%)
	No	5 (41.7%)
	Total valid response	12 (100.0%)
	Total missing	18
i) Stroke problem	Yes	1 (11.1%)
	No	7 (77.8%)
	Don't	1 (11.1%)



Question	Response	Number of Respondents (%)	
	know/Not sure		
	Total valid response	9 (100.0%)	
	Total missing	21	
j) Hypertension/high blood pressure	Yes	9 (64.3%)	
	No	5 (35.7%)	
	Total valid response	14 (100.0%)	
	Total missing	16	
k) Diabetes	Yes	14 (100.0%)	
	Total valid response	14 (100.0%)	
	Total missing	16	
l) Cancer	No	9 (100.0%)	
	Total valid response	9 (100.0%)	
	Total missing	21	
m) Mental or emotional health	Yes	2 (20.0%)	
	No	7 (70.0%)	
	Don't know/Not sure	1 (10.0%)	
	Total valid response	10 (100.0%)	
	Total missing	20	

### PT 1.2

Analysis Sets	Number of Respondents (%)
All valid respondents	10 (100.0%)
Included in Provider Analysis Set (PAS)	10 (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	10

Analysis Sets	Number of Respondents (%)
Included in the Eye Care Professional Set (Eye Specialist)	7 (70.0%)
Excluded in the Eye Care Professional Set (Eye Specialist)	3 (30.0%)
Reasons for exclusion from Eye Care Professional Set:	
Missing required speciality	3
No valid (non-missing) response for the supplemental eye questionnaire	0

### PT 1.3

Subgroups	Number of Respondents (%)
Provider Analysis Set	10 (100.0%)
Primary Care Provider	0 (0.0%)
Diabetes Specialist Provider	1 (10.0%)
Eye Care Professional	7 (70.0%)
Ophthalmologist	7 (70.0%)

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

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

#### PT 1.4

Item	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
What is your specialty?	General primary care/Family practitioner	N/A	0 (0.0%)	0 (0.0%)	0 (0.0%)
	Diabetes specialist	N/A	1 (100.0%)	0 (0.0%)	1 (10.0%)
	General ophthalmologist	N/A	0 (0.0%)	5 (71.4%)	5 (50.0%)
	Optometrist	N/A	0 (0.0%)	0 (0.0%)	0 (0.0%)
	Retinal specialist	N/A	0 (0.0%)	3 (42.9%)	3 (30.0%)
	Nurse	N/A	0 (0.0%)	0 (0.0%)	0 (0.0%)
	Health educator	N/A	0 (0.0%)	0 (0.0%)	0 (0.0%)
	None of the above	N/A	0 (0.0%)	0 (0.0%)	2 (20.0%)
	Total valid response	0 (100.0%)	1 (100.0%)	7 (100.0%)	10 (100.0%)
	Total missing	0	0	0	0

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)		1	7	10
	Mean		18.0	13.6	11.3
	SD			10.0	10.2
	Median		18.0	11.0	10.5
	Min.		18	0	0
	Max.		18	27	27
	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%)	1 (100.0%)	0 (0.0%)	1 (11.1%)
	Eye clinic/practice	0 (0.0%)	0 (0.0%)	3 (42.9%)	3 (33.3%)
	General medical clinic/practice	0 (0.0%)	0 (0.0%)	1 (14.3%)	1 (11.1%)
	Hospital	0 (0.0%)	0 (0.0%)	3 (42.9%)	3 (33.3%)
	Other	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (11.1%)
	Total Valid Response	0 (0.0%)	1 (100.0%)	7 (100.0%)	9 (100.0%)
	Total missing	0	0	0	1

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Where is your main practice	Urban setting	0 (0.0%)	1 (100.0%)	7 (100.0%)	9 (100.0%)

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
located?					
	Non-urban setting	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	Total Valid Response	0 (0.0%)	1 (100.0%)	7 (100.0%)	9 (100.0%)
	Total missing	0	0	0	1

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
In which sector is your main practice?	Government	0 (0.0%)	0 (0.0%)	1 (14.3%)	1 (11.1%)
	Private	0 (0.0%)	0 (0.0%)	5 (71.4%)	5 (55.6%)
	Non profit	0 (0.0%)	1 (100.0%)	0 (0.0%)	1 (11.1%)
	Combined/mixed	0 (0.0%)	0 (0.0%)	1 (14.3%)	2 (22.2%)
	Total Valid Response	0 (0.0%)	1 (100.0%)	7 (100.0%)	9 (100.0%)
	Total missing	0	0	0	1

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Is your main practice limited to certain populations?	No	0 (0.0%)	0 (0.0%)	7 (100.0%)	8 (88.9%)
	Yes, limited by age	0 (0.0%)	1 (100.0%)	0 (0.0%)	1 (11.1%)
	Yes, limited to persons with health insurance	0 (0.0%)	1 (100.0%)	0 (0.0%)	1 (11.1%)
	Yes, limited to low income or	0 (0.0%)	1 (100.0%)	0 (0.0%)	1



Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	uninsured persons				(11.1%)
	Total valid response	0	1 (100.0%)	7 (100.0%)	9 (100.0%)
	Total missing	0	0	0	1

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	0 (0.0%)	0 (0.0%)	1 (16.7%)	1 (14.3%)
	More than 1 week but less than 1 month	0 (0.0%)	0 (0.0%)	5 (83.3%)	5 (71.4%)
	Six or more months	0 (0.0%)	1 (100.0%)	0 (0.0%)	1 (14.3%)
	Total Valid Response	0 (0.0%)	1 (100.0%)	6 (100.0%)	7 (100.0%)
	Total missing	0	0	1	3

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)	0	1	6	7
	Mean	N/A	20	91.7	81.4
	SD	N/A		35.4	42.2
	Median	N/A	20	75	70
	Min.	N/A	20	60	20
	Max.	N/A	20	150	150
	Total missing	0	0	1	3

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
What percentage of the patients in your main practice have diabetes [% patients]	Total valid response (n)	0	1	6	7
	Mean	N/A	20	28.3	27.1
	SD	N/A		19.7	18.2
	Median	N/A	20	25	20
	Min.	N/A	20	10	10
	Max.	N/A	20	65	65
	Total missing	0	0	1	3

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?	Pay a reduced/subsidized rate	0 (0.0%)	1 (100.0%)	0 (0.0%)	1 (14.3%)
	Pay out-of-pocket (full fees)	0 (0.0%)	0 (0.0%)	2 (33.3%)	2 (28.6%)
	Pay through insurance	0 (0.0%)	0 (0.0%)	4 (66.7%)	4 (57.1%)
	Patient pays some, insurance pays some	0 (0.0%)	0 (0.0%)	5 (83.3%)	5 (71.4%)
	Total valid response	0	1 (100.0%)	6 (100.0%)	7 (100.0%)
	Total missing	0	0	1	3

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
In addition to your main practice, do you work in	Yes			3 (50.0%)	3 (42.9%)



Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
another practice setting?					
	No		1 (100.0%)	3 (50.0%)	4 (57.1%)
	Total valid response		1 (100.0%)	6 (100.0%)	7 (100.0%)
	Total missing			1	3
In which other practice setting(s) do you work?	Eye clinic/practice			2 (66.7%)	2 (66.7%)
	Other			1 (33.3%)	1 (33.3%)
	Total valid response			3 (100.0%)	3 (100.0%)
	Total missing		1	4	7
In which sector(s) is(are) the practice(s)?	Private			3 (100.0%)	3 (100.0%)
	Total valid response			3 (100.0%)	3 (100.0%)
	Total missing		1	4	7
Is there a major difference between your practices with respect to how diabetic eye disease is screened and managed?	No			3 (100.0%)	3 (100.0%)
	Total valid response			3 (100.0%)	3 (100.0%)
	Total missing		1	4	7

Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Blood glucose	Yes			1 (100.0%)	3 (50.0%)	4 (57.1%)
		Total valid numeric response (n)		0 (0.0%)	3 (50.0%)	3 (42.9%)
		Mean			6.0	6.0

Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
		SD			6.0	6.0
		Median			6.0	6.0
		Min			0	0
		Max			12	12
		Total missing		1	4	7
	No		1		3 (50.0%)	3 (42.9%)
	Total valid response			1 (100.0%)	6 (100.0%)	7 (100.0%)
	Total missing				1	3
HbA1c	Yes			1 (100.0%)	2 (33.3%)	3 (42.9%)
		Total valid numeric response (n)		0 (0.0%)	2 (33.3%)	2 (28.6%)
		Mean			2.0	2.0
		SD			0.0	0.0
		Median			2.0	2.0
		Min			2	2
		Max			2	2
		Total missing		1	5	8
	No		1		4 (66.7%)	4 (57.1%)
	Total valid response			1 (100.0%)	6 (100.0%)	7 (100.0%)
	Total missing				1	3
Urine check	Yes			1 (100.0%)	3 (50.0%)	4 (57.1%)
		Total valid numeric response (n)		0 (0.0%)	3 (50.0%)	3 (42.9%)



Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
		Mean			2.7	2.7
		SD			3.1	3.1
		Median			2.0	2.0
		Min			0	0
		Max			6	6
		Total missing		1	4	7
	No		1		3 (50.0%)	3 (42.9%)
	Total valid response			1 (100.0%)	6 (100.0%)	7 (100.0%)
	Total missing				1	3
Weight check	Yes			1 (100.0%)	2 (33.3%)	3 (42.9%)
		Total valid numeric response (n)		0 (0.0%)	2 (33.3%)	2 (28.6%)
		Mean			1.5	1.5
		SD			0.7	0.7
		Median			1.5	1.5
		Min			1	1
		Max			2	2
		Total missing		1	5	8
	No		•		4 (66.7%)	4 (57.1%)
	Total valid response			1 (100.0%)	6 (100.0%)	7 (100.0%)
	Total missing			1	1	3
Blood pressure check	Yes			1 (100.0%)	3 (50.0%)	4 (57.1%)
	1	Total valid numeric		0 (0.0%)	3 (50.0%)	3 (42.9%)

Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
		response (n)				
		Mean			4.0	4.0
		SD			6.9	6.9
		Median			0.0	0.0
		Min			0	0
		Max			12	12
		Total missing		1	4	7
	No				3 (50.0%)	3 (42.9%)
	Total valid response			1 (100.0%)	6 (100.0%)	7 (100.0%)
	Total missing				1	3
Foot check	Yes			1 (100.0%)		1 (14.3%)
	•			0 (0.0%)	0 (0.0%)	0 (0.0%)
		Mean				
		SD				
		Median				
		Min				
		Max				
		Total missing		1	7	10
	No		•		6 (100.0%)	6 (85.7%)
	Total valid response			1 (100.0%)	6 (100.0%)	7 (100.0%)
	Total missing				1	3
Eye examination - Un-dilated	Yes			1 (100.0%)	6 (100.0%)	7 (100.0%)
	,	Total valid numeric		0 (0.0%)	6 (100.0%)	6 (85.7%)



Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
		response (n)				
		Mean			2.8	2.8
		SD			4.5	4.5
		Median			1.0	1.0
		Min			0	0
		Max			12	12
		Total missing		1	1	4
	Total valid response		1	1 (100.0%)	6 (100.0%)	7 (100.0%)
	Total missing				1	3
Eye examination - Optical Coherence Tomography	Yes				6 (100.0%)	6 (85.7%)
		Total valid numeric response (n)		0 (0.0%)	6 (100.0%)	6 (85.7%)
		Mean			1.7	1.7
		SD			1.0	1.0
		Median			2.0	2.0
		Min			0	0
		Max			3	3
		Total missing		1	1	4
	No		1	1 (100.0%)		1 (14.3%)
	Total valid response			1 (100.0%)	6 (100.0%)	7 (100.0%)
	Total missing				1	3
Eye examination - Fundoscopy	Yes				6 (100.0%)	6 (85.7%)

Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
		Total valid numeric response (n)		0 (0.0%)	6 (100.0%)	6 (85.7%)
		Mean			2.3	2.3
		SD			1.6	1.6
		Median			2.0	2.0
		Min			0	0
		Max			5	5
		Total missing		1	1	4
	No		•	1 (100.0%)		1 (14.3%)
	Total valid response			1 (100.0%)	6 (100.0%)	7 (100.0%)
	Total missing				1	3
Eye examination - Fluorescein Angiography	Yes				6 (100.0%)	6 (85.7%)
		Total valid numeric response (n)		0 (0.0%)	6 (100.0%)	6 (85.7%)
		Mean			1.2	1.2
		SD			0.8	0.8
		Median			1.0	1.0
		Min			0	0
		Max			2	2
		Total missing		1	1	4
	No		-	1 (100.0%)		1 (14.3%)
	Total valid response			1 (100.0%)	6 (100.0%)	7 (100.0%)
	Total missing				1	3



Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Eye examination - Lipid check	Yes				3 (50.0%)	3 (42.9%)
		Total valid numeric response (n)		0 (0.0%)	3 (50.0%)	3 (42.9%)
		Mean			1.3	1.3
		SD			0.6	0.6
		Median			1.0	1.0
		Min			1	1
		Max			2	2
		Total missing		1	4	7
	No		ı	1 (100.0%)	3 (50.0%)	4 (57.1%)
	Total valid response			1 (100.0%)	6 (100.0%)	7 (100.0%)
	Total missing				1	3

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	0 (0.0%)	0 (0.0%)	3 (50.0%)	3 (50.0%)
	Diet/nutrition	0 (0.0%)	0 (0.0%)	1 (16.7%)	1 (16.7%)
	Exercise/physical activity	0 (0.0%)	0 (0.0%)	2 (33.3%)	2 (33.3%)
	Medicines	0 (0.0%)	0 (0.0%)	2 (33.3%)	2 (33.3%)
	Foot care and inspection	0 (0.0%)	0 (0.0%)	1 (16.7%)	1 (16.7%)

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Blood pressure	0 (0.0%)	0 (0.0%)	2 (33.3%)	2 (33.3%)
	Eye care and exams	0 (0.0%)	0 (0.0%)	6 (100.0%)	6 (100.0%)
	Lipid check	0 (0.0%)	0 (0.0%)	2 (33.3%)	2 (33.3%)
	Total valid response	0	0	6 (100.0%)	6 (100.0%)
	Total missing	0	1	1	4

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Is there written information about diabetes available for patients in your main practice?	Yes, and information on eye complications is sufficient	0 (0.0%)	0 (0.0%)	3 (50.0%)	3 (50.0%)
	No written information is available for patients	0 (0.0%)	0 (0.0%)	3 (50.0%)	3 (50.0%)
	Total Valid Response	0 (0.0%)	0	6 (100.0%)	6 (100.0%)
	Total missing	0	1	1	4

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	0 (0.0%)	0 (0.0%)	2 (33.3%)	2 (33.3%)
	Not available	0 (0.0%)	0 (0.0%)	4 (66.7%)	4 (66.7%)
	Total Valid	0 (0.0%)	0	6 (100.0%)	6



Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Response				(100.0%)
	Total missing	0	1	1	4

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%)	0 (0.0%)	3 (50.0%)	3 (50.0%)
	Not available	0 (0.0%)	0 (0.0%)	2 (33.3%)	2 (33.3%)
	Don't know/Not sure	0 (0.0%)	0 (0.0%)	1 (16.7%)	1 (16.7%)
	Total Valid Response	0 (0.0%)	0	6 (100.0%)	6 (100.0%)
	Total missing	0	1	1	4

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)		0	2 (33.3%)	2 (33.3%)
	Mean			5.0	5.0
	SD			0.0	0.0
	Median			5.0	5.0
	Min			5	5

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Max			5	5
	After a predetermined age (numeric response) (n)		0	0 (0.0%)	0 (0.0%)
	Mean				
	SD				
	Median				
	Min				
	Max				
	As soon as they are diagnosed			3 (50.0%)	3 (50.0%)
	No standard practice, timing varies case by case			1 (16.7%)	1 (16.7%)
	Total valid response			6 (100.0%)	6 (100.0%)
	Total missing		1	1	4
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 (0.0%)
	Mean				
	SD				
	Median				
	Min				
	Max				
	After a predetermined age (numeric response) (n)		0	0 (0.0%)	0 (0.0%)
	Mean				
	SD				
	Median				



Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Min				
	Max				
	As soon as they are diagnosed			5 (83.3%)	5 (83.3%)
	No standard practice, timing varies case by case			1 (16.7%)	1 (16.7%)
	Total valid response			6 (100.0%)	6 (100.0%)
	Total missing		1	1	4

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	0 (0.0%)	0 (0.0%)	6 (100.0%)	6 (100.0%)
	Total Valid Response	0 (0.0%)	0	6 (100.0%)	6 (100.0%)
	Total missing	0	1	1	4

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Do you screen patients for DR?	Yes			6 (100.0%)	6 (100.0%)
	Total valid response			6 (100.0%)	6 (100.0%)
	Total missing		1	1	4
Where do you screen patients?	In clinic			6 (100.0%)	6 (100.0%)
	Outreach			1 (16.7%)	1 (16.7%)
	Total valid			6 (100.0%)	6

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	response				(100.0%)
	Total missing		1	1	4

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
What patient characteristics influence your vision care and/or vision referrals?	Diabetes duration	0 (0.0%)	0 (0.0%)	5 (83.3%)	5 (83.3%)
	Patient's age	0 (0.0%)	0 (0.0%)	2 (33.3%)	2 (33.3%)
	Patient's gender	0 (0.0%)	0 (0.0%)	1 (16.7%)	1 (16.7%)
	Presence of comorbidities such as hypertension, etc.	0 (0.0%)	0 (0.0%)	4 (66.7%)	4 (66.7%)
	High glucose levels	0 (0.0%)	0 (0.0%)	5 (83.3%)	5 (83.3%)
	Patient educational level	0 (0.0%)	0 (0.0%)	2 (33.3%)	2 (33.3%)
	Patient adherence to recommendations	0 (0.0%)	0 (0.0%)	2 (33.3%)	2 (33.3%)
	Total valid response	0	0	6 (100.0%)	6 (100.0%)
	Total missing	0	1	1	4

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	Cost of care	0 (0.0%)	0 (0.0%)	1 (16.7%)	1 (16.7%)



Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
main practice?					
	Proximity to care	0 (0.0%)	0 (0.0%)	2 (33.3%)	2 (33.3%)
	Referral process	0 (0.0%)	0 (0.0%)	4 (66.7%)	4 (66.7%)
	Recommended treatments are not available	0 (0.0%)	0 (0.0%)	1 (16.7%)	1 (16.7%)
	Lack of knowledge and/or awareness	0 (0.0%)	0 (0.0%)	4 (66.7%)	4 (66.7%)
	Patients fear of treatment/results	0 (0.0%)	0 (0.0%)	4 (66.7%)	4 (66.7%)
	Patients they are a burden on family/friends	0 (0.0%)	0 (0.0%)	1 (16.7%)	1 (16.7%)
	Limited access to diabetes specialists	0 (0.0%)	0 (0.0%)	2 (33.3%)	2 (33.3%)
	Limited access to eye specialists	0 (0.0%)	0 (0.0%)	3 (50.0%)	3 (50.0%)
	Patients feel eye complications are unlikely	0 (0.0%)	0 (0.0%)	3 (50.0%)	3 (50.0%)
	Patients feel eye exams are not important	0 (0.0%)	0 (0.0%)	3 (50.0%)	3 (50.0%)
	Patients have competing responsibilities and priorities	0 (0.0%)	0 (0.0%)	1 (16.7%)	1 (16.7%)
	Total valid response	0	0	6 (100.0%)	6 (100.0%)
	Total missing	0	1	1	4

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
In your main practice, are patients contacted with reminders for general	Yes	0 (0.0%)	0 (0.0%)	1 (16.7%)	1 (16.7%)

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
follow-up appointments?					
	No	0 (0.0%)	0 (0.0%)	5 (83.3%)	5 (83.3%)
	Total Valid Response	0 (0.0%)	0	6 (100.0%)	6 (100.0%)
	Total missing	0	1	1	4

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	0 (0.0%)	0 (0.0%)	3 (50.0%)	3 (50.0%)
	No	0 (0.0%)	0 (0.0%)	2 (33.3%)	2 (33.3%)
	Don't know/Not sure	0 (0.0%)	0 (0.0%)	1 (16.7%)	1 (16.7%)
	Total Valid Response	0 (0.0%)	0	6 (100.0%)	6 (100.0%)
	Total missing	0	1	1	4

## PT 3.1

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Please indicate	30 - 39			2 (33.3%)	2
your age:					(33.3%)
	40 - 49			2 (33.3%)	2 (33.3%)
	50 - 59			1 (16.7%)	1 (16.7%)
	70 - 79			1 (16.7%)	1



Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
					(16.7%)
	Total valid response			6 (100.0%)	6 (100.0%)
	Total missing		1	1	4
What is your gender?	Female			4 (66.7%)	4 (66.7%)
	Male			2 (33.3%)	2 (33.3%)
	Total valid response			6 (100.0%)	6 (100.0%)
	Total missing		1	1	4
What is your highest level of education completed?	Graduate or advanced degree (e.g. PhD, MD, etc)			6 (100.0%)	6 (100.0%)
	Total valid response			6 (100.0%)	6 (100.0%)
	Total missing		1	1	4

Question	Response	Ophthalmologist
What percentage of your patients have diabetic retinopathy	Total valid numeric response (n)	6
	Mean	19.2
	SD	17.7
	Median	17.5
	Min	0
	Max	50
	Total missing	1

Question	Response	Ophthalmologist
What percentage of your patients have diabetic macular edema?	Total valid numeric response (n)	6
	Mean	12.5

Question	Response	Ophthalmologist
	SD	13.7
	Median	10.0
	Min	0
	Max	35
	Total missing	1

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	2 (33.3%)
	More than 1 week but less than 1 month	3 (50.0%)
	Do not take appointment	1 (16.7%)
	Total Valid Response	6 (100.0%)
	Total missing	1

#### PT 4.4

Question	Response	Ophthalmologist
From the time a patient is screened, what is the average length of time he/she waits for diagnosis?	Less than 1 week	4 (66.7%)
	There is not wait, diagnosis is given when screened	2 (33.3%)
	Total Valid Response	6 (100.0%)
	Total missing	1

Type of Treatment	Question	Response/time	Ophthalmologist
Laser photocoagulation	Is the treatment available?	Available within country	2 (33.3%)
		Available locally	1 (16.7%)
		Available in practice	5 (83.3%)
		Total valid response	6 (100.0%)



Type of Treatment	Question	Response/time	Ophthalmologist
		Total missing	1
	What is the average amount of time your patients wait for a consultation appointment? (weeks)	Total valid numeric response (n)	5 (100.0%)
		Mean	1.8
		SD	1.3
		Median	1.0
		Min	1
		Max	4
		Total valid response	5 (100.0%)
		Total missing	2
	What is the average amount of time your patients wait for a first treatment?(weeks)	Total valid numeric response (n)	6 (100.0%)
		Mean	1.2
		SD	0.4
		Median	1.0
		Min	1
		Max	2
		Total valid response	6 (100.0%)
		Total missing	1
	What is the average amount of time your patients wait for a second treatment?(weeks)	Total valid numeric response (n)	5 (100.0%)
		Mean	2.2
		SD	1.6
		Median	1.0
		Min	1
		Max	4
		Total valid response	5 (100.0%)
		Total missing	2
Anti-VEGF therapies	Is the treatment available?	Available within country	2 (33.3%)
		Available locally	1 (16.7%)

Type of Treatment	Question	Response/time	Ophthalmologist
		Available in practice	5 (83.3%)
		Total valid response	6 (100.0%)
		Total missing	1
	What is the average amount of time your patients wait for a consultation appointment? (weeks)	Total valid numeric response (n)	5 (100.0%)
		Mean	2.0
		SD	1.2
		Median	2.0
		Min	1
		Max	4
		Total valid response	5 (100.0%)
		Total missing	2
	What is the average amount of time your patients wait for a first treatment?(weeks)	Total valid numeric response (n)	6 (100.0%)
		Mean	1.3
		SD	0.5
		Median	1.0
		Min	1
		Max	2
		Total valid response	6 (100.0%)
		Total missing	1
	What is the average amount of time your patients wait for a second treatment?(weeks)	Total valid numeric response (n)	5 (100.0%)
		Mean	2.2
		SD	1.6
		Median	1.0
		Min	1
		Max	4
		Total valid response	5 (100.0%)



Type of Treatment	Question	Response/time	Ophthalmologist
		Total missing	2
Intravitreal steroid	Is the treatment available?	Available within country	3 (50.0%)
		Available locally	1 (16.7%)
		Available in practice	4 (66.7%)
		Total valid response	6 (100.0%)
		Total missing	1
	What is the average amount of time your patients wait for a consultation appointment? (weeks)	Total valid numeric response (n)	4 (80.0%)
		Mean	2.0
		SD	1.4
		Median	1.5
		Min	1
		Max	4
		Not applicable	1 (20.0%)
		Total valid response	5 (100.0%)
		Total missing	2
	What is the average amount of time your patients wait for a first treatment?(weeks)	Total valid numeric response (n)	5 (83.3%)
		Mean	1.2
		SD	0.4
		Median	1.0
		Min	1
		Max	2
		Not applicable	1 (16.7%)
		Total valid response	6 (100.0%)
		Total missing	1
	What is the average amount of time your patients wait for a second treatment?(weeks)	Total valid numeric response (n)	4 (80.0%)
		Mean	2.8

Type of Treatment	Question	Response/time	Ophthalmologist
		SD	3.5
		Median	1.0
		Min	1
		Max	8
		Not applicable	1 (20.0%)
		Total valid response	5 (100.0%)
		Total missing	2
Uncomplicated vitrectomy	Is the treatment available?	Available within country	2 (33.3%)
		Available locally	1 (16.7%)
		Available in practice	4 (66.7%)
		Not available	1 (16.7%)
		Total valid response	6 (100.0%)
		Total missing	1
	What is the average amount of time your patients wait for a consultation appointment? (weeks)	Total valid numeric response (n)	5 (100.0%)
		Mean	4.2
		SD	4.5
		Median	2.0
		Min	1
		Max	12
		Total valid response	5 (100.0%)
		Total missing	2
	What is the average amount of time your patients wait for a first treatment?(weeks)	Total valid numeric response (n)	5 (100.0%)
		Mean	4.2
		SD	4.5
		Median	2.0
		Min	1
		Max	12



Type of Treatment	Question	Response/time	Ophthalmologist
		Total valid response	5 (100.0%)
		Total missing	2
	What is the average amount of time your patients wait for a second treatment?(weeks)	Total valid numeric response (n)	3 (75.0%)
		Mean	2.0
		SD	0.0
		Median	2.0
		Min	2
		Max	2
		Don't know/not sure	1 (25.0%)
		Total valid response	4 (100.0%)
		Total missing	3
Complex vitreo- retinal surgery	Is the treatment available?	Available within country	3 (50.0%)
	I	Available locally	1 (16.7%)
		Available in practice	3 (50.0%)
		Not available	1 (16.7%)
		Total valid response	6 (100.0%)
		Total missing	1
	What is the average amount of time your patients wait for a consultation appointment? (weeks)	Total valid numeric response (n)	5 (100.0%)
		Mean	3.4
		SD	2.4
		Median	2.0
		Min	1
		Max	6
		Total valid response	5 (100.0%)
		Total missing	2
	What is the average amount of time your patients wait for a first	Total valid numeric	5 (100.0%)

Type of Treatment	Question	Response/time	Ophthalmologist
	treatment?(weeks)	response (n)	
		Mean	3.4
		SD	2.4
		Median	2.0
		Min	1
		Max	6
		Total valid response	5 (100.0%)
		Total missing	2
	What is the average amount of time your patients wait for a second treatment?(weeks)	Total valid numeric response (n)	3 (75.0%)
		Mean	2.0
		SD	0.0
		Median	2.0
		Min	2
		Max	2
		Don't know/not sure	1 (25.0%)
		Total valid response	4 (100.0%)
		Total missing	3

Question	Response	Ophthalmologist
Do you personally administer treatment for diabetic retinopathy?	Yes	6 (100.0%)
	Total valid response	6 (100.0%)
	Total missing	1
Who administer it?	Total missing	7

Question	Response	Ophthalmologist
Do any of the following influence how you	Diabetes duration	4 (66.7%)
treat diabetic retinopathy or diabetic macular		



Question	Response	Ophthalmologist
edema?		
	Patient's age	2 (33.3%)
	Patient's gender	1 (16.7%)
	Presence of comorbidities such as hypertension, etc.	5 (83.3%)
	High glucose levels	4 (66.7%)
	Ability or inability to pay	3 (50.0%)
	Insurance restrictions	1 (16.7%)
	Patient educational level	4 (66.7%)
	Patient adherence to recommendations	4 (66.7%)
	Total valid response	6 (100.0%)
	Total missing	1

Question	Response	Ophthalmologist
Do you treat diabetic retinopathy and diabetic macular edema based on:	Both	6 (100.0%)
	Total Valid Response	6 (100.0%)
	Total missing	1

# PT 4.9

Question	Response	Ophthalmologist
How are your patients with diabetes screened for diabetic eye disease?	Fundoscopy dilated	6 (100.0%)
	Retinal photo	3 (50.0%)
	Optical Coherence Tomography	6 (100.0%)
	Fluorescein Angiography	6 (100.0%)
	Total valid response	6 (100.0%)
	Total missing	1

Question	Response	Ophthalmologist

Question	Response	Ophthalmologist
In your opinion, do the majority of your patients present:	When visual problems have already occurred	6 (100.0%)
	Total Valid Response	6 (100.0%)
	Total missing	1

Question	Response	Ophthalmologist
Have you received training specifically on treatment and diagnosis of diabetic retinopathy and/or clinically significant diabetic macular edema?	Yes	5 (83.3%)
	No	1 (16.7%)
	Total valid response	6 (100.0%)
	Total missing	1
If yes, When was your last training?	Greater than 1 year ago but less than 5 years	2 (40.0%)
	Within the past year	3 (60.0%)
	Total valid response	5 (100.0%)
	Total missing	2

# PT 4.12

Question	Response	Ophthalmologist
Would you be interested in online education and certification on DME, Angiogenesis and Anti-VEGF therapies?	Yes	6 (100.0%)
	Total Valid Response	6 (100.0%)
	Total missing	1

Question	Response	Ophthalmologist
How is outreach for screening for diabetic eye disease done in your main practice?	At vision centers	3 (50.0%)
	Not done	2 (33.3%)
	Don't know/Not sure	1 (16.7%)
	Total valid response	6 (100.0%)



Question	Response	Ophthalmologist
	Total missing	1

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	3 (50.0%)
	Late diagnosis	6 (100.0%)
	Referral pathways	5 (83.3%)
	Limited access to patient education on diabetic retinopathy and diabetic macular edema	5 (83.3%)
	No universal guidelines on referral/screening	2 (33.3%)
	No universal guidelines on how to treat	1 (16.7%)
	No universal guideline on when to treat	1 (16.7%)
	Current available therapies not effective	1 (16.7%)
	Government/insurance not able to cover patient costs	4 (66.7%)
	Multi-disciplinary team integration is poor	5 (83.3%)
	Ineffective screening services	3 (50.0%)
	Total valid response	6 (100.0%)
	Total missing	1

Question	Response	Without DED (%)	With DED (%)	With DME (%)
Which of the following complications of diabetes do you have?	Foot ulcers	1 (12.5%)	3 (20.0%)	1 (16.7%)
	Kidney disease	1 (12.5%)	1 (6.7%)	3 (50.0%)
	Loss of feeling in hands or toes (neuropathy)	3 (37.5%)	11 (73.3%)	3 (50.0%)
	Cardiovascular disease/Stroke	0 (0.0%)	4 (26.7%)	1 (16.7%)
	Irritable bowel disease	0 (0.0%)	1 (6.7%)	1 (16.7%)

Question	Response	Without DED (%)	With DED (%)	With DME (%)
	Vision loss	0 (0.0%)	10 (66.7%)	3 (50.0%)
	Amputation	0 (0.0%)	0 (0.0%)	1 (16.7%)
	Broken bones or fractures	0 (0.0%)	2 (13.3%)	0 (0.0%)
	Other	0 (0.0%)	0 (0.0%)	2 (33.3%)
	None	3 (37.5%)	0 (0.0%)	0 (0.0%)
	Don't know/Not sure	2 (25.0%)	0 (0.0%)	0 (0.0%)
	Total Valid Response	8 (100.0%)	15 (100.0%)	6 (100.0%)
	Total missing	1	0	0

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

Limitations	Without DED n (%)	With DED n (%)	With DME n (%)
Limited in any way in any activities because of impairment or health problem	1 (14.3%)	6 (40.0%)	3 (50.0%)
Impairment or health problem		•	
Diabetes	1 (100.0%)	9 (100.0%)	4 (100.0%)
Back or neck problem	1 (50.0%)	2 (40.0%)	3 (75.0%)
Eye/vision problem	1 (50.0%)	6 (100.0%)	4 (100.0%)
Hypertension/high blood pressure	1 (50.0%)	4 (50.0%)	4 (100.0%)
Walking problem	0 (0.0%)	3 (50.0%)	3 (100.0%)
Lung/breathing problem	0 (0.0%)	1 (20.0%)	2 (66.7%)
Hearing problem	0 (0.0%)	1 (20.0%)	1 (25.0%)
Heart problem	0 (0.0%)	3 (42.9%)	4 (100.0%)
Mental or emotional health	0 (0.0%)	1 (20.0%)	1 (25.0%)
Stroke problem	0 (0.0%)	0 (0.0%)	1 (33.3%)
Fractures, bone/joint injury	0 (0.0%)	3 (42.9%)	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 [2]: DED = respondents with DED ="Yes" minus respondents with DME ="Yes".

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

 $<sup>{\</sup>it NB~[4]: Percentages~within~groups~are~calculated~from~non-missing~data~for~that~question.}$ 

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

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



Health Status	Without DED (%)	With DED (%)	With DME (%)
Self-rated health: Good	5 (71.4%)	6 (40.0%)	1 (20.0%)
Self-rated health: Poor	2 (28.6%)	9 (60.0%)	4 (80.0%)
Physically unhealthy days	5 (83.3%)	5 (83.3%)	1 (50.0%)
Mentally unhealthy days	3 (50.0%)	2 (33.3%)	1 (50.0%)
Unhealthy days	5 (83.3%)	5 (83.3%)	1 (50.0%)
Activity limitation days	4 (80.0%)	2 (25.0%)	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	18 (60.0%)	15 (65.2%)	3 (42.9%)
	Oral medicine	5 (16.7%)	2 (8.7%)	3 (42.9%)
	Exercise	14 (46.7%)	13 (56.5%)	1 (14.3%)
	Insulin	28 (93.3%)	23 (100.0%)	5 (71.4%)
	Natural/Herbal medicine	3 (10.0%)	3 (13.0%)	

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	4 (50.0%)	9 (60.0%)	2 (33.3%)
	Volunteering	1 (12.5%)	0 (0.0%)	1 (16.7%)
	Retired	1 (12.5%)	3 (20.0%)	3 (50.0%)
	Student	1 (12.5%)	1 (6.7%)	0 (0.0%)
	Not working	1 (12.5%)	2 (13.3%)	0 (0.0%)
	Total Valid Response	8 (100.0%)	15 (100.0%)	6 (100.0%)
	Total missing	1	0	0
Do you receive assistance from the government?	Income assistance	1 (12.5%)	1 (7.7%)	1 (16.7%)
	Medical assistance	0 (0.0%)	5 (38.5%)	1 (16.7%)

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 (%)
	Housing assistance	0 (0.0%)	0 (0.0%)	1 (16.7%)
	Pension assistance	4 (50.0%)	7 (53.8%)	4 (66.7%)
	None of the above	4 (50.0%)	4 (30.8%)	1 (16.7%)
	Total valid response	8 (100.0%)	13 (100.0%)	6 (100.0%)
	Total missing	1	2	0
Did you have trouble paying for food at anytime during the past year?	Yes	2 (25.0%)	7 (46.7%)	2 (33.3%)
	No	6 (75.0%)	8 (53.3%)	4 (66.7%)
	Total Valid Response	8 (100.0%)	15 (100.0%)	6 (100.0%)
	Total missing	1	0	0

EXP 5.2: Age group 18-39 years

Item	Response	Without DED (%)	With DED (%)	With DME (%)
Are you currently working?	Working for pay	4 (80.0%)	4 (50.0%)	0 (0.0%)
	Retired	0 (0.0%)	1 (12.5%)	0 (0.0%)
	Student	1 (20.0%)	1 (12.5%)	0 (0.0%)
	Not working	0 (0.0%)	2 (25.0%)	0 (0.0%)
	Total Valid Response	5 (100.0%)	8 (100.0%)	0 (0.0%)
Do you receive assistance from the government?	Income assistance	0 (0.0%)	1 (12.5%)	0 (0.0%)
	Medical assistance	0 (0.0%)	2 (25.0%)	0 (0.0%)
	Pension assistance	3 (60.0%)	5 (62.5%)	0 (0.0%)
	None of the above	2 (40.0%)	3 (37.5%)	0 (0.0%)
	Total valid	5 (100.0%)	8 (100.0%)	0

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

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

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

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



Item	Response	Without DED (%)	With DED (%)	With DME (%)
	response			
	Total missing	0	0	0
Did you have trouble paying for food at anytime during the past year?	Yes	1 (20.0%)	4 (50.0%)	0 (0.0%)
	No	4 (80.0%)	4 (50.0%)	0 (0.0%)
	Total Valid Response	5 (100.0%)	8 (100.0%)	0 (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 DED (%)	With DED (%)	With DME (%)
Are you currently working?	Working for pay	0 (0.0%)	4 (80.0%)	1 (100.0%)
	Volunteering	1 (50.0%)	0 (0.0%)	0 (0.0%)
	Retired	1 (50.0%)	1 (20.0%)	0 (0.0%)
	Total Valid Response	2 (100.0%)	5 (100.0%)	1 (100.0%)
	Total missing	1	0	0
Do you receive assistance from the government?	Income assistance	1 (50.0%)	0 (0.0%)	0 (0.0%)
	Medical assistance	0 (0.0%)	3 (75.0%)	0 (0.0%)
	Pension assistance	1 (50.0%)	1 (25.0%)	1 (100.0%)
	None of the above	1 (50.0%)	1 (25.0%)	0 (0.0%)
	Total valid response	2 (100.0%)	4 (100.0%)	1 (100.0%)
	Total missing	1	1	0
Did you have trouble paying for food at anytime during the past year?	Yes	1 (50.0%)	2 (40.0%)	1 (100.0%)
	No	1 (50.0%)	3 (60.0%)	0 (0.0%)
	Total Valid Response	2 (100.0%)	5 (100.0%)	1 (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 [2]: DED = respondents with DED ="Yes" minus respondents with DME ="Yes".

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

EXP 5.4: Age group 60-79 years

Item	Response	Without DED (%)	With DED (%)	With DME (%)
Are you currently working?	Working for pay	0 (0.0%)	1 (50.0%)	1 (25.0%)
	Volunteering	0 (0.0%)	0 (0.0%)	1 (25.0%)
	Retired	0 (0.0%)	1 (50.0%)	2 (50.0%)
	Not working	1 (100.0%)	0 (0.0%)	0 (0.0%)
	Total Valid Response	1 (100.0%)	2 (100.0%)	4 (100.0%)
Do you receive assistance from the government?	Income assistance	0 (0.0%)	0 (0.0%)	1 (25.0%)
	Medical assistance	0 (0.0%)	0 (0.0%)	1 (25.0%)
	Housing assistance	0 (0.0%)	0 (0.0%)	1 (25.0%)
	Pension assistance	0 (0.0%)	1 (100.0%)	2 (50.0%)
	None of the above	1 (100.0%)	0 (0.0%)	1 (25.0%)
	Total valid response	1 (100.0%)	1 (100.0%)	4 (100.0%)
	Total missing	0	1	0
Did you have trouble paying for food at anytime during the past year?	Yes	0 (0.0%)	1 (50.0%)	1 (25.0%)
	No	1 (100.0%)	1 (50.0%)	3 (75.0%)
	Total Valid Response	1 (100.0%)	2 (100.0%)	4 (100.0%)

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

EXP 5.5: Age group 80+ years

Item	Response	Without DED (%)	With DED (%)	With DME (%)
Are you currently working?	Retired	0 (0.0%)	0 (0.0%)	1 (100.0%)
	Total Valid Response	0 (0.0%)	0 (0.0%)	1 (100.0%)
Do you receive assistance from the government?	Pension assistance	0 (0.0%)	0 (0.0%)	1 (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 valid response	0	0	1 (100.0%)
	Total missing	0	0	0
Did you have trouble paying for food at anytime during the past year?	No	0 (0.0%)	0 (0.0%)	1 (100.0%)
	Total Valid Response	0 (0.0%)	0 (0.0%)	1 (100.0%)

NB [1]: Without DED = respondents who did not select "Yes" for both DED and DME.
NB [2]: DED = respondents with DED ="Yes" minus respondents with DME ="Yes".
NB [3]: DME = respondents with DME ="Yes".

Group	Subgroup	All respondents	Type 1 diabetes	Type 2 diabetes	With DED (%)	With DME (%)
All respondents		30 (100%)	23 (76.7%)	7 (23.3%)	15 (50.0%)	6 (20.0%)
Gender	Male	12 (41.4%)	8 (66.7%)	4 (33.3%)	5 (41.7%)	5 (41.7%)
	Female	17 (58.6%)	14 (82.4%)	3 (17.6%)	10 (58.8%)	1 (5.9%)
	Total Missing	1	1	0	0	0
Age	18-39 yrs	13 (43.3%)	13 (100.0%)	0 (0.0%)	8 (61.5%)	0 (0.0%)
	40-59 yrs	9 (30.0%)	6 (66.7%)	3 (33.3%)	5 (55.6%)	1 (11.1%)
	60-79 yrs	7 (23.3%)	3 (42.9%)	4 (57.1%)	2 (28.6%)	4 (57.1%)
	80 yrs and over	1 (3.3%)	1 (100.0%)	0 (0.0%)	0 (0.0%)	1 (100.0%)
Time since diagnosis	Within the last year	1 (3.3%)	1 (100.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	1 - 5 years ago	1 (3.3%)	0 (0.0%)	1 (100.0%)	1 (100.0%)	0 (0.0%)
	6 - 10 years ago	4 (13.3%)	2 (50.0%)	2 (50.0%)	1 (25.0%)	1 (25.0%)
	11 - 15 years ago	4 (13.3%)	1 (25.0%)	3 (75.0%)	3 (75.0%)	1 (25.0%)
	16 - 20 years ago	6 (20.0%)	6 (100.0%)	0 (0.0%)	1 (16.7%)	1 (16.7%)
	21 years ago or longer	14 (46.7%)	13 (92.9%)	1 (7.1%)	9 (64.3%)	3 (21.4%)
Control of	Controlled	14 (46.7%)	12 (85.7%)	2 (14.3%)	7 (50.0%)	3 (21.4%)

Group	Subgroup	All respondents	Type 1 diabetes	Type 2 diabetes	With DED (%)	With DME (%)
Diabetes						
	Not controlled	16 (53.3%)	11 (68.8%)	5 (31.3%)	8 (50.0%)	3 (18.8%)

Question	Response	With DED n (%)	With DME n (%)
Have you had any treatment for diabetic eye disease?	Yes	13 (86.7%)	5 (83.3%)
	No	2 (13.3%)	1 (16.7%)
	Total valid response	15 (100.0%)	6 (100.0%)
What treatment did you receive?	Laser	12 (92.3%)	5 (100.0%)
	Anti-VEGF	1 (7.7%)	2 (40.0%)
	Surgery	3 (23.1%)	2 (40.0%)
	Other	1 (7.7%)	1 (20.0%)
	Total valid response	13 (100.0%)	5 (100.0%)
	Total missing	2	1
Did you complete the treatment?	Yes	3 (23.1%)	2 (40.0%)
	No	2 (15.4%)	0 (0.0%)
	Still receiving treatment	8 (61.5%)	3 (60.0%)
	Total valid response	13 (100.0%)	5 (100.0%)
	Total missing	2	1
Do you feel that the treatment worked?	Yes, and vision improved	3 (27.3%)	1 (20.0%)
	Yes, but vision stayed the same	5 (45.5%)	4 (80.0%)
	Still waiting to know	1 (9.1%)	0 (0.0%)
	Don't know/Not sure	2 (18.2%)	0 (0.0%)
	Total valid response	11 (100.0%)	5 (100.0%)
	Total missing	4	1
What is/are the reason(s) that you did not	Eye doctor was located	1 (50.0%)	0 (0.0%)

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

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

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



Question	Response	With DED n (%)	With DME n (%)
complete the treatment?	too far away		
	Other	2 (100.0%)	0 (0.0%)
	Total valid response	2 (100.0%)	0 (0.0%)
	Total missing	13	6
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%)	0 (0.0%)
	Treatment would not be effective	0 (0.0%)	1 (100.0%)
	Total valid response	2 (100.0%)	1 (100.0%)
	Total missing	13	5

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

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

 $NB~\cite{Barrier} \begin{tabular}{ll} NB~\cite{Barrier} \begin{tabular}{ll} Percentages~within~groups~are~calculated~from~non-missing~data~for~that~question. \end{tabular}$ 











