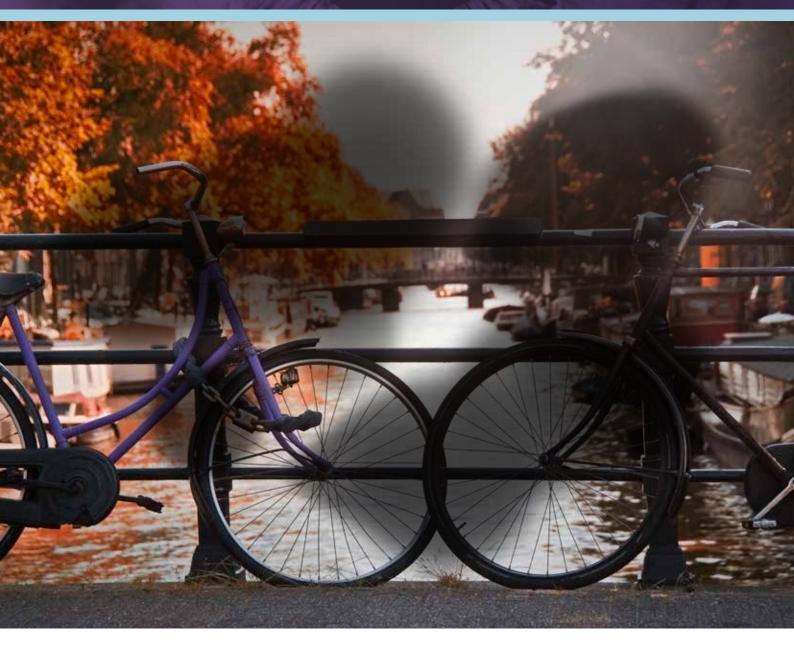


# The Diabetic Retinopathy Barometer Report **Netherlands**











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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, multicountry 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 the Netherlands.

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

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

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

## Goal

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

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

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

## Background

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

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 the WBIGs.

### **Study Populations**

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

Even though the sample is not representative of the broader population of people with diabetes and health care professionals, the findings illustrate important trends, and highlight areas of concern. The results from this survey provide new evidence reflecting concerns from the voices of thousands of patients and health care professionals around the world. This study provides a rich resource for generating unique insights into the real-life experiences of people living with diabetes, and as such is a powerful tool to help improve the lives of current and future generations of people with diabetes.

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

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

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

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



# Introduction Netherlands Study

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

The Netherlands is estimated to be the eighth most populous country in the European Union and twelfth most populous country in Europe with a population of approximately 16.9 million. According to most recent statistics it is estimated that ~16% of the population is under the age of 15 and ~18% over the age of 65.

Despite the Netherlands currently having a large ageing population, high life expectancy, and low fertilities rates, the Netherland's population is expected to slowly and steadily increase during the next few decades. By 2050, it is expected that the Netherland's population will be 17.2 million with those under the age of 15 making up 15% of the total population and those aged 65 and older will make up 28% of the total population. This means that in just over 30 years' time, the Netherland's population over the age of 65 will increase by ~51%, from 3.1 million to 4.8 million.

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

There are 415 million people living with diabetes and more than 59.8 million people are in the European region. By 2040, this number is expected to rise to 71.1 million. Fifty-six countries comprise the European region with diverse populations ranging from Norway, the Russian Federation, Turkey, and Iceland. While the European region has the second-lowest age-adjusted comparative diabetes prevalence rate of any IDF region (after Africa), there are still many countries with relatively high diabetes prevalence rates.

The Netherlands has over 973,500 (724.6-1,195.5‡) adults living with diabetes, which accounts to ~1.6% of people living with diabetes in the region. The diabetes national prevalence in the Netherlands (20 – 79 years) is 7.9% (5.9-9.7‡) and the diabetes age-adjusted comparative prevalence is 5.5% (4.0-7.1).

Deaths attributed to diabetes in the Netherlands in 2015 were 7,574 which accounts to ~1.2% of the diabetes-related deaths experienced in the region. The estimated number of undiagnosed cases was 367,500 (375.5-619.5‡).

## Study Populations: Netherlands

As reported by 79 respondents with diabetes in the Netherlands, 7.6% were diagnosed with DED and a further 2.5% with DME.

Seventeen health care professionals completed the survey in the Netherlands. Of these, one was a diabetes specialist (5.9%) and 13 were ophthalmologists

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

The DR Barometer study was conducted in 41 countries. In the Netherlands, 79 adults with diabetes and 17 health care professionals provided new information about the experiences of living with, managing and treating diabetes, DR and DME.

14%

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



# 29%

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









IHI

# 57%

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







# 86%

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



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



36%

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

# 29%

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

## **Netherlands DR Barometer Findings:** Adults with Diabetes

### Key Demographic Characteristics

Seventy-nine adults with diabetes completed the patients' survey in the Netherlands: 41% were female and 60% were male (see Table 1). Fiftysix percent lived in an urban setting and 44% in a non-urban setting (see Appendix Table 4.2).

The education levels of all respondents were as follows: 8% of respondents were educated to a primary school level, 52% to a secondary school level, 37% to a college or university level, and 2.7% to a graduate or postgraduate level (see Appendix Table 4.3).

Thirty-six percent of all respondents were in paid employment, 29% were retired, and 29% were not working (see Appendix Table 4.4).

Most respondents (48%) were aged between 40 and 59 years (7.6% were 18-39 years, 42% were 60-79 years and 2.5% were 80 years and over). Fifty-six percent were of traditional working age (18- 59 years).

Of the respondents in the Netherlands, 14% had been diagnosed with type 1 diabetes and 82% with type 2 diabetes. A further 3.8% of respondents were either unsure of or did not know their type of diabetes (see Appendix Table 2.1).

Six respondent (7.6%) reported they had been diagnosed with DED and a further 2.5% (n=2) with DME. Six percent of those surveyed were diagnosed with diabetes within the last year, 1 - 5 years ago (38%), 6 - 10 years ago (24%), 11 - 15 years ago (17%), 16 - 20 years ago (5.1%) and 21 years ago or more (8.9%) (see Appendix Table 2.2).

A younger population was more likely to be associated with type 1 diabetes, which was the opposite of those with type 2 diabetes, which tended to be an older population.

Amongst 18 to 39-year-olds, 50% had type 1 and 33% had type 2 diabetes. In the 40-59 age group, 11% had type 1 and 87% had type 2 diabetes. Twelve percent of 60-79-yearolds had type 1 diabetes and 85% had type 2.

In people aged 18-39 years no one had DED and 17% (n=1) had DME. For the 40-59 year age group, 11% (n=4) had DED and 2.6% (n=1) had DME, and in the 60-79 year age group 6.1% (n=2) had DED no one had DME.

In those diagnosed with diabetes within the last five years 7% (n=2) had DED. Twentynine percent (n=2) of respondents diagnosed more than 21 years had DED.

While most (83%) respondents reported that their diabetes was well controlled there were almost one in six (15%) who felt that this was not the case. For those with good control, 6.5% (n=4) had DED and 1.6% (n=1) had DME and in those whose diabetes was reported not well controlled 9.1% (n=1) had DED and 9.1% (n=1) had DME.

Group	Subgroup	All Respondents	Type 1 diabetes	Type 2 diabetes	With DED	With DME
All respondents		79 (100.0%)	11 (13.9%)	65 (82.3%)	6 (7.6%)	2 (2.5%)
Gender	Male	44 (59.5%)	5 (11.4%)	38 (86.4%)	2 (4.5%)	1 (2.3%)
	Female	30 (40.5%)	4 (13.3%)	25 (83.3%)	3 (10.0%)	1 (3.3%)
	Total Missing	5	2	2	1	0
Age	18-39 yrs.	6 (7.6%)	3 (50.0%)	2 (33.3%)	0 (0.0%)	1 (16.7%)
	40-59 yrs.	38 (48.1%)	4 (10.5%)	33 (86.8%)	4 (10.5%)	1 (2.6%)
	60-79 yrs.	33 (41.8%)	4 (12.1%)	28 (84.8%)	2 (6.1%)	0 (0.0%)
	80 yrs. plus	2 (2.5%)	0 (0.0%)	2 (100.0%)	0 (0.0%)	0 (0.0%)
Time since diagnosis	Within the last year	5 (6.3%)	1 (20.0%)	3 (60.0%)	0 (0.0%)	0 (0.0%)
	1 - 5 yrs.	30 (38.0%)	3 (10.0%)	26 (86.7%)	2 (6.7%)	2 (6.7%)
	6 - 10 yrs.	19 (24.1%)	0 (0.0%)	19 (100.0%)	1 (5.3%)	0 (0.0%)
	11 - 15 yrs.	13 (16.5%)	2 (15.4%)	11 (84.6%)	0 (0.0%)	0 (0.0%)
	16 - 20 yrs.	4 (5.1%)	2 (50.0%)	2 (50.0%)	1 (25.0%)	0 (0.0%)
	21 yrs. plus	7 (8.9%)	3 (42.9%)	3 (42.9%)	2 (28.6%)	0 (0.0%)
	Don't know/ Not sure	1 (1.3%)	0 (0.0%)	1 (100.0%)	0 (0.0%)	0 (0.0%)
Control of Diabetes	Controlled	62 (82.7%)	8 (12.9%)	53 (85.5%)	4 (6.5%)	1 (1.6%)
	Not controlled	11 (14.7%)	1 (9.1%)	10 (90.9%)	1 (9.1%)	1 (9.1%)
	Don't know/ Not sure	2 (2.7%)	0 (0.0%)	1 (50.0%)	0 (0.0%)	0 (0.0%)
	Total Missing	4	2	1	1	0
	Total Missing	25	12	12	1	0

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

NB [1]: Percentages for All Respondents category are calculated based on their respective group. All categories are calculated as row percentages. NB [2]: Diabetes control is based on the respondents' perception of their own control. Diabetes control terms were grouped as follows; Controlled includes patients who selected 'Very Well' and 'Well'. Not Controlled includes patients who selected 'Not very well' and 'Not well at all'.

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

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

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

#### Knowledge and Management of Diabetes

Ninety-four percent of those surveyed saw a health care professional for their diabetes, with 25% seeing a diabetes specialist (average number of visits was 3 times per year) and 27% seeing a general or family doctor (average number of visits was 3.8 times per year) (see Appendix Table 2.3.1 and 2.3.2).

People were informed about their condition through a variety of channels. Ninety-two percent received information from their doctor or nurse, 34% from the internet and 33% from a nutritionist or dietician (see Table 2 and Appendix Table 2.4).

# Table 2: Source of informationregarding diabetes

Information Source	All Respondents (n=77)
Doctor or nurse	71 (92.2%)
Internet	26 (33.8%)
Nutritionist or dietician	25 (32.5%)
Diabetes organisation or other health organisation	20 (26.0%)
Pharmacist	12 (15.6%)
Health educator	9 (11.7%)
Family/Friends/Neighbours	6 (7.8%)
TV/Radio/Newspaper/Magazines	4 (5.2%)
Social media (e.g. Facebook, Twitter, blogs)	4 (5.2%)

A range of strategies was used by respondents to manage their diabetes. For those with type 1 diabetes, apart from insulin, 50% managed their diabetes with diet, 50% with exercise, and 40% with oral medicine. Of the respondents with type 2 diabetes, 69% reported that they managed their condition with oral medicine, 44% with diet, 39% with exercise, and 34% with insulin.

Twenty-two percent of respondents were enrolled in diabetes management programmes and all said the programme included information 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 (92%), these occurred at the following intervals: less than 6 months (35%), 6 - 12 months (47%), and greater than 12 months (11%) (see Appendix Table 2.7).

The main challenges in controlling diabetes cited by respondents were: the person did not want to think about having diabetes (29%), the cost of care (28%), it was too hard to eat the right things (21%), it was difficult to travel to their regular doctor or specialist (19%) and there were too many other things to do (12%) (see Appendix Table 2.9).

Health education and information (24%), coordination of healthcare and services by a professional (23%), free or low cost medicines or monitoring materials (20%), support from family or friends (15%) and emergency helpline (5.3%) were identified as important to improving the management of their diabetes. For 39% of respondents none of the services offered were helpful to their management of diabetes (see Appendix Table 2.10).



# Nature and Information about Complications

Sixty-seven percent of respondents were aware of amputation and other complications, such as: vision loss (61%), neuropathy (60%), cardiovascular disease or stroke (57%), and foot ulcers (49%) were associated with diabetes (see Appendix Table 2.11).

Respondents were most concerned about vision loss (19%), cardiovascular disease or stroke (17%), neuropathy (11%), amputation (9.3%), and kidney disease (4%) (see Appendix Table 2.12).

Forty-nine percent of respondents reported that they had no complications of diabetes. However, of those who did have complications 28% had neuropathy, cardiovascular disease or stroke (15%), vision loss (9.3%), kidney disease (6.7%), and foot ulcers (5.3%) (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 complications compared to people without DED, although it is noted that the sample size was small. The frequency of neuropathy increased from 25% in those without DED to 60% with DED and 50% in those with DME; as with the reporting of cardiovascular disease increasing from 12% for those without DED to 40% in those with DED and to 50% with DME (see Table 3 and Appendix EXP 1).

100 90 80 70 Percent [%] 60 50 40 30 20 10 Ω None Foot ulcers Other Cardiovascular disease/Stroke Kidney disease Amputation oss of feeling in hands or toes (neuropathy) Vision loss

#### Figure 1: Presence of complications

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

Complication	Without DED (n=68)	With DED (n=5)	With DME (n=2)
Any	31 (45.6%)	5 (100.0%)	2 (100.0%)
Loss of feeling in hands or toes (neuropathy)	17 (25.0%)	3 (60.0%)	1 (50.0%)
Vision loss	3 (4.4%)	3 (60.0%)	1 (50.0%)
Cardiovascular disease/Stroke	8 (11.8%)	2 (40.0%)	1 (50.0%)
Foot ulcers	2 (2.9%)	2 (40.0%)	0 (0.0%)
Kidney disease	3 (4.4%)	1 (20.0%)	1 (50.0%)
Amputation	2 (2.9%)	0 (0.0%)	0 (0.0%)
Other	1 (1.5%)	0 (0.0%)	0 (0.0%)
None	37 (54.4%)	0 (0.0%)	0 (0.0%)

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

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

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

 $\mathsf{NB}$  [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

Eighty-eight percent of respondents stated that eye complications were discussed with their health care professionals. Notwithstanding this, nearly one in three patients (29%) either never discussed eye complications with their health care provider (12%) or discussion only took place only once symptoms arose (17%). The frequency of regular discussions varied from every visit (9.3%), multiple times a year (13%), and for almost half (48%) of the respondents only once a year (see Appendix Table 2.14). Less than half of all patients (47%) reported that they did what they could to prevent vision problems (e.g. get routine screenings, visit specialists). Yet myths and perceptions around vision changes and preventions were evident with an alarming 43% who thought that vision problems were a normal part of ageing and one in five (21%) who do not make any special efforts to prevent vision problems (see Appendix Table 2.15).

Thirty-five percent of all respondents had received information about DR and DME, with their doctor or nurse being the most common source (27%). A concerning finding was that almost two-thirds of respondents did not receive such information from any of the traditional sources listed, including their doctor or nurse (73%) (see Table 4 and Appendix Table 3.9).

# Table 4: Source of information about DR and DME

Source	All respondents (n=75)
Doctor/Nurse	20 (26.7%)
Diabetes organisation or other health organisation	7 (9.3%)
Health educator	3 (4.0%)
Internet	3 (4.0%)
TV/Radio/Newspaper/Magazines	2 (2.7%)
None of the above	49 (65.3%)

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 (83%) respondents reported having had an eye exam for DED, with 73% having the exam within the last year and a further 22% between one and two years. Over threequarters of respondents were aware of government sponsored screening programmes for DED (see Appendix Table 3.1 and 3.2).

While 67% of those surveyed thought they should have their eyes examined for DED once a year there were over a quarter (26%) of respondents who reported that testing should happen every two years (see Appendix Table 3.4).

The biggest barriers to eye exams were long wait times for an appointment (14%), respondents did not know enough about their condition (10%), and the cost of the exam (8.6%) (see Table 5 and Appendix Table 3.5).

#### Table 5: Barriers to eye examinations

Identified Barriers	All Respondents (n=5)
Long wait time for appointment	10 (14.3%)
Don't know much about my condition	7 (10.0%)
They are expensive	6 (8.6%)
Long wait time on the day of the visit	6 (8.6%)
Fear of treatment/results	5 (7.1%)
I'm not likely to have eye complications	5 (7.1%)
Too many other things to do or worry about	5 (7.1%)
Recommended treatments for eye problems are not available	2 (2.9%)
Limited access to diabetes specialists	2 (2.9%)
Eye exams are not important	1 (1.4%)
Other	36 (51.4%)

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

Treatment was assessed separately in

people with DED and in those with DME. Fifty-percent (n=3) of those with DED received treatment with the most common treatment being laser (67%). Two thirds had completed treatment, one respondent was still undergoing treatment, and two-thirds felt that treatment had been successful and their vision had stayed the same (see Table 6).

For the three respondents with DED who had not received treatment, the most common reason reported was that their doctor did not recommend treatment.

Both of the respondents with DME (n=2) had received treatment and with 50% receiving laser and/or anti-VEGF therapy. One respondent completed the treatment, and felt it was successful and their vision improved, while the other respondent did not as they were fearful of the treatment.

One respondent with DME said they would prefer proactive treatment to prevent further vision loss and the other respondent preferred reactive treatment only when further vision loss had occurred (see Appendix Table 3.8).

	3 (50.0%) 3 (50.0%) 2 (66.7%)	2 (100.0%) 0 (0.0%)
		0 (0.0%)
	2 [66.7%]	
	- (,	1 (50.0%)
EGF	0 (0.0%)	1 (50.0%)
	1 (33.3%)	0 (0.0%)
	2 (66.7%)	1 (50.0%)
	0 (0.0%)	1 (50.0%)
eceiving treatment	1 (33.3%)	0 (0.0%)
nd vision improved	0 (0.0%)	1 (100.0%)
ut vision stayed the	2 (66.7%)	0 (0.0%)
aiting to know	1 (33.3%)	0 (0.0%)
earful (scared) of nent	0 (0.0%)	1 (100.0%)
ctor did not mend any treatment	1 (50.0%)	0 (0.0%)
nent would not be ve	1 (50.0%)	0 (0.0%)
nent is not accessible	1 (50.0%)	0 (0.0%)
	acceiving treatment ad vision improved ut vision stayed the aiting to know earful (scared) of eent ctor did not mend any treatment hent would not be ve	EGF       0 (0.0%)         1 (33.3%)       2 (66.7%)         0 (0.0%)       0 (0.0%)         acceiving treatment       1 (33.3%)         ad vision improved       0 (0.0%)         ut vision stayed the       2 (66.7%)         aiting to know       1 (33.3%)         earful (scared) of ment       0 (0.0%)         ctor did not mend any treatment       1 (50.0%)         nent would not be we       1 (50.0%)

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

NNB [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

All respondents diagnosed with DED or DME said that their vision was affected (25% significantly, 75% slightly) (see Appendix Table 3.6).

Eighty-six percent of these respondents reported that vision issues impacted their daily lives in various ways such as managing their underlying diabetes (57%), working or keeping a job (43%), social interactions with family or friends (29%), driving a vehicle (29%), household responsibilities, such as cooking or cleaning (14%), and leisure activities or exercising (14%) (see Table 7).

# Table 7: Activities affected through visionimpairment and loss

	All Respondents (n=7)
Managing my diabetes	4 (57.1%)
Work or keeping a job	3 (42.9%)
Social interactions with family/ friends	2 (28.6%)
Driving (a car/vehicle)	2 (28.6%)
Household responsibilities, such as cooking or cleaning	1 (14.3%)
Leisure activities/exercise	1 (14.3%)
None	1 (14.3%)

Forty percent of those with DED and 50% with DME were in paid employment compared with 35% of respondents without DED (see Table 8 and Appendix EXP 5.1). Patients with vision complications reported difficulties with work or keeping a job (43%) and 40% (n=2) of those with DED were not working.

Seventy-six percent of all those surveyed did not receive assistance from the government while 11% received income assistance (see Appendix Table 4.5). The proportion of respondents without DED who received assistance from the government was 22%, this proportion increased to 40% in those with DED.

An important finding to note, 45% of respondents reported to have had trouble paying for food at some point during the past year including both respondents with DME (see Appendix Table 4.6).

Eighty-four percent of respondents stated that they did not feel access to health care was affected by any factors, however, for 11% it was affected by their age (see Appendix Table 4.7).

Thirty-five percent of respondents said they worried about their health, followed by money (32%), and family (5.3%) (see Appendix Table 4.8).

Working without pay at home (e.g. housework, farming)         2 (2.9%)         0 (0.0%)         0 (0.0%)           Volunteering         1 (1.5%)         0 (0.0%)         0 (0.0%)           Retired         21 (30.9%)         1 (20.0%)         0 (0.0%)           Student         1 (1.5%)         0 (0.0%)         0 (0.0%)           Not working         19 (27.9%)         2 (40.0%)         1 (50.0%)           Question         Response         Without DED (n=68)         With DED (n=5)         With DME (n=2)           Do you receive assistance from the government?         Income assistance         8 (11.8%)         0 (0.0%)         0 (0.0%)           Medical assistance         2 (2.9%)         2 (40.0%)         1 (50.0%)           Food assistance         2 (2.9%)         0 (0.0%)         0 (0.0%)           Housing assistance         2 (2.9%)         0 (0.0%)         0 (0.0%)           Housing assistance         2 (2.9%)         0 (0.0%)         0 (0.0%)           Pension assistance         3 (4.4%)         1 (20.0%)         0 (0.0%)           None of the above         53 (77.9%)         3 (60.0%)         1 (50.0%)           Question         Response         Without DED (n=67)         With DED (n=5)         With DME (n=2)           Did you hav	Question	Response	Without DED (n=68)	With DED (n=5)	With DME (n=2)
pay at home (e.g. housework, farming)         2 (2.9%)         0 (0.0%)         0 (0.0%)           Volunteering         1 (1.5%)         0 (0.0%)         0 (0.0%)           Retired         21 (30.9%)         1 (20.0%)         0 (0.0%)           Student         1 (1.5%)         0 (0.0%)         0 (0.0%)           Not working         19 (27.9%)         2 (40.0%)         1 (50.0%)           Question         Response         Without DED (n=68)         With DED (n=5)         With DME (n=2)           Do you receive assistance from the government?         Income assistance         8 (11.8%)         0 (0.0%)         0 (0.0%)           Medical assistance         2 (2.9%)         2 (40.0%)         1 (50.0%)           Food assistance         2 (2.9%)         0 (0.0%)         0 (0.0%)           Housing assistance         2 (2.9%)         0 (0.0%)         0 (0.0%)           Housing assistance         2 (2.9%)         0 (0.0%)         0 (0.0%)           Pension assistance         3 (4.4%)         1 (20.0%)         0 (0.0%)           Question         Response         Without DED (n=67)         With DED (n=5)         With DME (n=2)           Did you have trouble paying for food at any time during the past year?         Yes         2 (40.3%)         2 (40.0%)	Are you currently working?	Working for pay	24 (35.3%)	2 (40.0%)	1 (50.0%)
Retired         21 [30.9%]         1 [20.0%]         0 [0.0%]           Student         1 [1.5%]         0 [0.0%]         0 [0.0%]           Not working         19 [27.9%]         2 [40.0%]         1 [50.0%]           Question         Response         Without DED (n=68)         With DED (n=5)         With DME (n=2)           Do you receive assistance from the government?         Income assistance         8 [11.8%]         0 (0.0%)         0 (0.0%)           Medical assistance         2 [2.9%]         2 [40.0%]         1 [50.0%]           Food assistance         2 [2.9%]         0 (0.0%]         0 (0.0%]           Housing assistance         2 [2.9%]         0 (0.0%]         0 (0.0%]           Medical assistance         2 [2.9%]         0 (0.0%]         0 (0.0%]           Housing assistance         2 [2.9%]         0 (0.0%]         0 (0.0%]           Housing assistance         2 [2.9%]         0 (0.0%]         0 (0.0%]           Medical assistance         3 [4.4%]         1 [20.0%]         0 (0.0%]           None of the above         53 [77.9%]         3 [60.0%]         1 [50.0%]           Question         Response         Without DED (n=67)         With DED (n=5)         With DME (n=2)           Did you have trouble paying for food at		pay at home (e.g.	2 (2.9%)	0 (0.0%)	0 (0.0%)
Student         1 [1.5%]         0 [0.0%]         0 [0.0%]           Not working         19 [27.9%]         2 [40.0%]         1 [50.0%]           Question         Response         Without DED (n=68)         With DED (n=5)         With DME (n=2)           Do you receive assistance from the government?         Income assistance         8 [11.8%]         0 [0.0%]         0 [0.0%]           Medical assistance         2 [2.9%]         2 [40.0%]         1 [50.0%]           Food assistance         2 [2.9%]         0 [0.0%]         0 [0.0%]           Housing assistance         2 [2.9%]         0 [0.0%]         0 [0.0%]           None of the above         3 [4.4%]         1 [20.0%]         0 [0.0%]           Question         Response         Without DED (n=67)         With DED (n=5)         With DME (n=2)           Did you have trouble paying for food at any time during the past year?         Yes         29 [43.3%]         2 [40.0%]         2 [100%]		Volunteering	1 (1.5%)	0 (0.0%)	0 (0.0%)
Not working         19 (27.9%)         2 (40.0%)         1 (50.0%)           Question         Response         Without DED (n=68)         With DED (n=5)         With DME (n=2)           Do you receive assistance from the government?         Income assistance         8 (11.8%)         0 (0.0%)         0 (0.0%)           Medical assistance         2 (2.9%)         2 (40.0%)         1 (50.0%)           Food assistance         2 (2.9%)         0 (0.0%)         0 (0.0%)           Housing assistance         2 (2.9%)         0 (0.0%)         0 (0.0%)           Mone of the above         53 (77.9%)         3 (60.0%)         1 (50.0%)           Question         Response         Without DED (n=67)         With DED (n=5)         With DME (n=2)           Did you have trouble paying for food at any time during the past year?         Yes         29 (43.3%)         2 (40.0%)         2 (100%)		Retired	21 (30.9%)	1 (20.0%)	0 (0.0%)
QuestionResponseWithout DED (n=68)With DED (n=5)With DME (n=2)Do you receive assistance from the government?Income assistance8 (11.8%)0 (0.0%)0 (0.0%)Medical assistance2 (2.9%)2 (40.0%)1 (50.0%)Food assistance2 (2.9%)0 (0.0%)0 (0.0%)Housing assistance2 (2.9%)0 (0.0%)0 (0.0%)Housing assistance2 (2.9%)0 (0.0%)0 (0.0%)Pension assistance3 (4.4%)1 (20.0%)0 (0.0%)None of the above53 (77.9%)3 (60.0%)1 (50.0%)QuestionResponseWithout DED (n=67)With DED (n=5)With DME (n=2)Did you have trouble paying for food at any time during the past year?Yes29 (43.3%)2 (40.0%)2 (100%)		Student	1 (1.5%)	0 (0.0%)	0 (0.0%)
Income assistance from the government?         Income assistance assistance         Income assistance 8 (11.8%)         Income (0.0%)         Income 0 (0.0%)           Medical assistance         2 (2.9%)         2 (40.0%)         1 (50.0%)           Medical assistance         2 (2.9%)         0 (0.0%)         0 (0.0%)           Food assistance         2 (2.9%)         0 (0.0%)         0 (0.0%)           Housing assistance         2 (2.9%)         0 (0.0%)         0 (0.0%)           Mone of the above         3 (4.4%)         1 (20.0%)         0 (0.0%)           None of the above         53 (77.9%)         3 (60.0%)         1 (50.0%)           Question         Response         Without DED (n=67)         With DED (n=5)         With DME (n=2)           Did you have trouble paying for food at any time during the past year?         Yes         29 (43.3%)         2 (40.0%)         2 (100%)		Not working	19 (27.9%)	2 (40.0%)	1 (50.0%)
the government?     8 (11.8%)     0 (0.0%)     0 (0.0%)       Medical assistance     2 (2.9%)     2 (40.0%)     1 (50.0%)       Food assistance     2 (2.9%)     0 (0.0%)     0 (0.0%)       Housing assistance     2 (2.9%)     0 (0.0%)     0 (0.0%)       Pension assistance     2 (2.9%)     0 (0.0%)     0 (0.0%)       None of the above     3 (4.4%)     1 (20.0%)     0 (0.0%)       Question     Response     Without DED (n=67)     With DED (n=5)     With DME (n=2)       Did you have trouble paying for food at any time during the past year?     Yes     29 (43.3%)     2 (40.0%)     2 (100%)	Question	Response			
Food assistance       2 (2.9%)       0 (0.0%)       0 (0.0%)         Housing assistance       2 (2.9%)       0 (0.0%)       0 (0.0%)         Pension assistance       3 (4.4%)       1 (20.0%)       0 (0.0%)         None of the above       53 (77.9%)       3 (60.0%)       1 (50.0%)         Question       Response       Without DED (n=67)       With DED (n=5)       With DME (n=2)         Did you have trouble paying for food at any time during the past year?       Yes       29 (43.3%)       2 (40.0%)       2 (100%)	Do you receive assistance from the government?	Income assistance	8 (11.8%)	0 (0.0%)	0 (0.0%)
Housing assistance       2 (2.9%)       0 (0.0%)       0 (0.0%)         Pension assistance       3 (4.4%)       1 (20.0%)       0 (0.0%)         None of the above       53 (77.9%)       3 (60.0%)       1 (50.0%)         Question       Response       Without DED (n=67)       With DED (n=5)       With DME (n=2)         Did you have trouble paying for food at any time during the past year?       Yes       29 (43.3%)       2 (40.0%)       2 (100%)		Medical assistance	2 (2.9%)	2 (40.0%)	1 (50.0%)
Pension assistance         3 [4.4%]         1 [20.0%]         0 [0.0%]           None of the above         53 [77.9%]         3 [60.0%]         1 [50.0%]           Question         Response         Without DED (n=67)         With DED (n=5)         With DME (n=2)           Did you have trouble paying for food at any time during the past year?         Yes         29 [43.3%]         2 [40.0%]         2 [100%]		Food assistance	2 (2.9%)	0 (0.0%)	0 (0.0%)
None of the above53 (77.9%)3 (60.0%)1 (50.0%)QuestionResponseWithout DED (n=67)With DED (n=5)With DME (n=2)Did you have trouble paying for food at any time during the past year?Yes 29 (43.3%)2 (40.0%)2 (100%)		Housing assistance	2 (2.9%)	0 (0.0%)	0 (0.0%)
QuestionResponseWithout DED (n=67)With DED (n=5)With DME (n=2)Did you have trouble paying for food at any time during the past year?Yes 29 (43.3%)2 (40.0%)2 (100%)		Pension assistance	3 (4.4%)	1 (20.0%)	0 (0.0%)
Image:		None of the above	53 (77.9%)	3 (60.0%)	1 (50.0%)
for food at any time during the     29 [43.3%]     2 [40.0%]     2 [100%]       past year?     2     2     2     2	Question	Response			
No 38 (56.7%) 3 (60.0%) 0 (0.0%)	Did you have trouble paying for food at any time during the past year?	Yes	29 (43.3%)	2 (40.0%)	2 (100%)
		No	38 (56.7%)	3 (60.0%)	0 (0.0%)

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

NNB [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).

Fifty-three percent of people without DED, and 67% of people with DED, reported that their health as poor. While reported health was reasonably consistent whether the respondent had DED or not and the respondent numbers were quite small, there was a 17% increase in the activity limitation days between those with DED and those without DED.

Compared with 41% of those without DED, all respondents with DED and DME experienced limitations to their daily activities due to poor health (see Appendix Table EXP 2).

Tuble 7. Sell Teporteur	Table 7. Set reported heating days of patients without DED, with DED of Diffe				
Health Status	Without DED	With DED	With DME		
Self-rated health: Good	31 (47.0%)	2 (40.0%)	1 (50.0%)		
Self-rated health: Poor	35 (53.0%)	3 (60.0%)	1 (50.0%)		
Physically unhealthy days	25 (43.9%)	3 (75.0%)	1 (100.0%)		
Mentally unhealthy days	20 (32.3%)	2 (100.0%)	1 (100.0%)		
Unhealthy days	33 (55.9%)	3 (100.0%)	1 (100.0%)		
Activity limitation days	18 (50.0%)	2 (66.7%)	1 (100.0%)		

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

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.

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

## **Key Demographic Characteristics**

There were 17 health care professionals who answered at least one of the survey questions in Netherlands. Of these one was a diabetes specialist provider (5.9%) and 13 were ophthalmologists (77%). The remaining respondents were nurses or other types of professionals (see Appendix PT 1.3).

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

Health care professionals as a group had been practicing for an average of 16 years (see Appendix PT 1.5).

Health care professionals were well educated (64% with graduate or advanced degree); 43% were female and 57% male, and varied in age categories with 57% between 40 - 59 years of age (see Table 10 and Appendix PT 3.1).

Group	Subgroup	All Respondents	Primary Care Provider	Diabetes Specialist	Ophthalmologist
All respondents		17 (100.0%)	1 (5.9%)	13 (76.5%)	10 (13.3%)
Age group	30 - 39 yrs.	3 (21.4%)	0 (0.0%)	3 (25.0%)	1 (14.3%)
	40 - 49 yrs.	4 (28.6%)	1 (100.0%)	2 (16.7%)	1 (14.3%)
	50 - 59 yrs.	4 (28.6%)	0 (0.0%)	4 (33.3%)	2 (28.6%)
	60 - 69 yrs.	3 (21.4%)	0 (0.0%)	3 (25.0%)	3 (42.9%)
Gender	Female	6 (42.9%)	0 (0.0%)	5 (41.7%)	0 (0.0%)
	Male	8 (57.1%)	1 (100.0%)	7 (58.3%)	0 (0.0%)
Education	College/University	5 (35.7%)	0 (0.0%)	4 (33.3%)	7 (100.0%)
	Graduate or advanced degree (e.g. PhD, MD, etc.)	9 (64.3%)	1 (100.0%)	8 (66.7%)	0 (0.0%)

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

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

Ninety-four percent of all providers, including all of the ophthalmologists, had their main practice setting in a hospital (see Appendix PT 2.1).

Ninety-four percent of health care professionals worked in an urban setting (see Appendix PT 2.2).

Most health care professionals worked in the government sector (41%) and ophthalmologists worked mainly in the government (39%), as well as a combined or mixed (31%) or nonprofit (23%) sector (see Appendix PT 2.3).

Health care professionals reported that 75% of patients pay through insurance for services, 19% pay some, and insurance pays the remainder, and 6.3% of patients do not pay for services (see Appendix PT 2.7).

On average, all providers see 105 patients per week and an estimated 31% of their patients had diabetes. Including ophthalmologists whom saw an average 135 patients per week and an average of 20% of their patients had diabetes (see Appendix PT 2.6). For all health care professionals, the average wait time for an appointment was most commonly less than one week (31%), or between one week and a month (25%) (see Appendix PT 2.5).

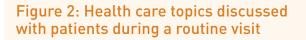
For an appointment with an ophthalmologist, it was usually between one and two months in a third of practices but in a quarter of practices, the average wait time was between one week and a month.

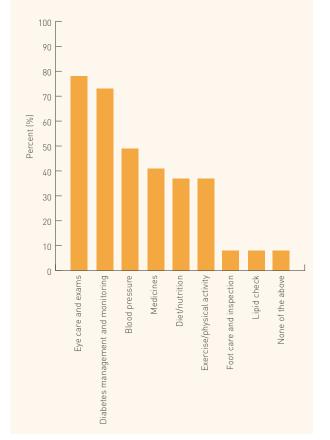
# Table 11: Average wait times to schedule an appointment

Wait Time Intervals	All Respondents (n=16)	Ophthalmologist (n=12)
Less than 1 week	5 (31.3%)	2 (16.7%)
More than 1 week but less than 1 month	4 (25.0%)	3 (25.0%)
More than 1 month but less than 2 months	4 (25.0%)	4 (33.3%)
More than 2 months but less than 3 months	3 (18.8%)	3 (25.0%)

### **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 is available yet the adequacy of that related to eye complications varies.

Over two-thirds of ophthalmologists (67%) had written information about diabetes and potential eye complications, 17% had information on diabetes but that which was on eye complications was insufficient and 8.3% reported that specific information on eye complications was not included. For the one diabetes specialist there was no information available for their patients regarding eye complications.

## **Guidelines and Protocols**

Fifty percent of ophthalmologists had written protocols for the management of diabetes, which were used by staff. However, 36% of all providers had no such protocols available (see Appendix PT 2.12).

With respect to the management of diabetes-related vision issues 75% of ophthalmologists had written protocols, which were used by staff. Twenty-nine percent of all providers did not have protocols on the management of diabetes-related vision issues available (see Table 12 and Appendix PT 2.13).

Question	Response	All Respondents (n=14)	Ophthalmologist (n=12)
Is there written information about diabetes available	Yes, and information on eye complications is sufficient	8 (57.1%)	8 (66.7%)
for patients in your main practice?	Yes, but information on eye complications is not sufficient	3 [21.4%]	2 (16.7%)
	Yes, but no information on eye complications is included	1 (7.1%)	1 (8.3%)
	No written information is available for patients	1 (7.1%)	0 (0.0%)
	Don't know/Not sure	1 (7.1%)	1 (8.3%)
Question	Response	All Respondents (n=14)	Ophthalmologist (n=12)
Do you have written protocols/guidelines for	Yes, available and used by staff	9 (64.3%)	9 (75.0%)
detection and management of diabetes-related vision issue available in your main practice?	Not available	4 (28.6%)	2 (16.7%)
	Don't know/Not sure	1 (7.1%)	1 (8.3%)
	Don't know/Not sure	5 (10.0%)	0 (0.0%)

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

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

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

Most providers, for patients with type 1 diabetes (43%), or type 2 diabetes (93%), recommended an initial eye exam at the time of diagnosis of diabetes. Forty-two percent of ophthalmologists recommended an initial eye exam for those with type 1 diabetes after a pre-determined number of years (average 5 years) (see Appendix PT 2.14).

Two-thirds of ophthalmologists reported that follow-up eye examinations were conducted every two years however, only a third of ophthalmologists send their patient's reminders to schedule an appointment (see Appendix PT 2.15 and PT 2.19). All health care professionals screen patients for DR and 92% shared patient relevant information with other providers to optimise patient care management (see Appendix PT 2.16 and PT 2.20).

The most common patient characteristics influencing the referral process for eye complications for all health professionals were: a patient's age (64%), the presence of comorbidities such as hypertension (64%), a patient's diabetes duration (57%), high glucose levels (57%), and a patient's ability to adhere to recommendations (36%) (see Appendix PT 2.17).

As reported by all health care professionals, including the ophthalmologists, the major barriers to optimising eye health faced by patients with diabetes were: the perception that patient's feel that eye complications are unlikely (43%), or that eye exams are not important (43%), and long wait times to schedule an appointment (14%) (see Table 13 and Appendix PT 2.18).



## Table 13: Major barriers to optimising eye health

Response	All Respondents (n=14)	Ophthalmologists (n=12)
Patients feel eye complications are unlikely	6 [42.9%]	6 (50.0%)
Patients feel eye exams are not important	6 (42.9%)	6 (50.0%)
Long wait time for appointment	2 (14.3%)	2 (16.7%)
Patients have competing responsibilities and priorities	2 (14.3%)	2 [16.7%]
Cost of care	1 (7.1%)	1 (8.3%)
Long wait time on the day of visit	1 (7.1%)	1 (8.3%)
Referral process	2 (14.3%)	1 (8.3%)
Patients fear of treatment/results	1 (7.1%)	1 (8.3%)
Clinic too small or lack necessary equipment/staff	1 (7.1%)	1 (8.3%)
Other	5 (35.7%)	4 (33.3%)

# **Netherlands DR Barometer Findings:** Ophthalmologists

## Screening

There were eight ophthalmologists who answered at least one of the supplementary questions (see Appendix PT 4.1 to PT 4.14). On average 17% of patients seen by the ophthalmologists had DR and 4% DME (see Appendix PT 4.1 and PT 4.2).

The most common waiting time for a screening appointment for DED was between one and two months (33%) with 25% between one week and under a month (see Appendix PT 4.3).

Forty-two percent of ophthalmologists reported a wait time from screening to diagnosis of less than one week, a third (n=4) reported a wait time between one week and under a month (see Appendix PT 4.4).

## **Treatment and Challenges**

Ninety-one percent of ophthalmologists personally administer treatment for DR (See Appendix PT 4.6).

The most common factors influencing how ophthalmologists treat patients with DR or DME were the presence of comorbidities such as hypertension (70%), high glucose levels (70%), and a patient's age (60%) (see Appendix PT 4.7).

The most common outreach venues for screening for DED were vision centres (40%), mobile screening centres (20%), and health fairs for all and for people with diabetes (10%) (see Appendix PT 4.13). Eighty-two percent of ophthalmologists reported that they screen patients for DR based on fundoscopy through dilated pupils. Additionally 55% use retinal photo and 55% use optical coherence tomography. All ophthalmologists reported that to treat DR and DME based on both visual and anatomical outcomes (see Appendix PT 4.8 and PT 4.9).

Ninety-one percent of ophthalmologists said that most patients present in time for screening although one respondent reported that patients present when visual problems have already occurred (see Appendix PT 4.10).

Sixty-four percent of ophthalmologists had received specific training on the treatment and diagnosis of DR and or DME. Fifty-seven percent had training between one and five years ago, 29% had training five years ago or more and 14% received the training within the past year (see Appendix PT 4.11).

Nonetheless, sixty-four percent would be interested in online education and certification on DME, angiogenesis and anti-VEGF therapies (see Appendix PT 4.12).

Although small in numbers, ophthalmologists reported that the greatest challenges for improving patient outcomes in DED were reimbursement restrictions on approved therapy (25%, n=2) and the complex referral pathways (25%, n=2) (see Table 14 and Appendix PT 4.14).



## Table 14: Challenges for improving outcomes in DED

Question	Response	Ophthalmologist (n=8)
What do you perceive to be the greatest challenges for improving	Reimbursement/restrictions on approved therapy	2 (25.0%)
patient outcomes in diabetic eye disease?	Referral pathways	2 (25.0%)
	Limited access to patient education on diabetic retinopathy and diabetic macular edema	2 (25.0%)
	Government/insurance not able to cover patient costs	2 (25.0%)
	Late diagnosis	1 (12.5%)
	No universal guidelines on referral/ screening	1 (12.5%)
	No universal guidelines on how to treat	1 (12.5%)
	No universal guideline on when to treat	1 (12.5%)
	Current available therapies not effective	1 (12.5%)
	Multi-disciplinary team integration is poor	1 (12.5%)
	Other	2 (25.0%)

# Netherlands DR Barometer Summary

In Netherlands, 79 adults with diabetes and 17 health care professionals have provided insight about their experiences of living with, managing and treating diabetes, DR and DME. The results help to improve the awareness, management, and services available in Netherlands.

The Netherlands is estimated to be the eighth most populous country in the European Union and twelfth most populous country in Europe with a population of approximately 16.9 million<sup>3</sup> and has over 973,500 (724.6-1,195.5‡) adults living with diabetes, which accounts to ~1.6% of people living with diabetes in the region<sup>4</sup>.

Despite the Netherlands currently having a large ageing population, high life expectancy, and low fertilities rates, the Netherland's population is expected to slowly and steadily increase during the next few decades. By 2050, it is expected that the Netherland's population over the age of 65 will increase by ~51%, from 3.1 million to 4.8 million<sup>5</sup>.

The DR Barometer findings indicate that a younger population was more likely to be associated with type 1 diabetes, which was the opposite of those with type 2 diabetes, which tended to be an older population. This is important, and well-known, finding in the context of the Netherlands ageing population.

People were most often informed about their diabetes condition from their health care professionals, such as a doctor or nurse, nutritionist or dietician although diabetes or other health organisations were also identified as important sources of information. A trend globally, which was reflected in the Netherlands study, was the increasing usage of the internet by a third of respondents. Many of those struggled with the management of their diabetic condition with some issues that were within their personal control such as acknowledging their condition, eating the right foods, and balancing their health with other priorities. Some challenges reported were beyond their control such as the cost of care or difficulty in travelling to their regular doctor or specialist.

It is a noteworthy finding that given a high percentage of respondents did not want to think about their diabetes there was also over a third who did not utilise any services to help them better manage their condition, such as support groups, and only 22% were currently enrolled in a diabetes management programme. Half of the ophthalmologists also reported a perception that people with diabetes in the Netherlands either did not feel that eye complications are likely or that eye exams were important.

Coinciding with this, a relatively low awareness, and concern, of various complications associated with diabetes, with one in four unaware of vision loss as a potential complication. It is also important to note nearly one in three patients (29%) either never discussed eye health with their health care providers or discussions only took place once symptoms arose.

Equally concerning is the myths and perceptions around vision changes and prevention strategies as less than half of all patients (47%) reported that they did what they could to prevent vision problems (e.g. get routine screenings, visit specialists). An alarming 43% thought that vision problems were a normal part of ageing and some one in five did not make any special efforts to prevent vision problems.

The relationship between the patient and their provider is critical to realistic and optimal patient outcomes. Health education



and information was reported by almost a quarter (24%) of patients as the most useful tool to improve the management of one's diabetes yet almost two-thirds of respondents had not received information regarding potential eye complications from any of the traditional sources, including their doctor or nurse.

Knowledge and guidance was not only an issue for patients as some, one in six ophthalmologists, reported not having any written protocols or guidelines available for the management of diabetes-related vision loss.

All respondents (n=7) diagnosed with DED or DME and reporting that their vision was either slightly or significantly affected in turn had an impact on their health, lifestyle, and life choices. One in two reported their vision impairment affected their ability to manage their underlying diabetes. For 43% their ability to work or keep a job was put in jeopardy, and for others their vision loss resulted in difficulty interacting with family and friends, driving a car, or maintaining household responsibilities, such as cooking or cleaning.

Although small in numbers there was an increase in the frequency of people with DED and DME experiencing certain complications beyond vision loss compared with those without DED. The frequency of neuropathy and cardiovascular or stroke had a marked increase in those with DED and DME.

Fifty-three percent of people without DED, and 67% of people with DED, reported that their health as poor. While reported health was reasonably consistent whether the respondent had DED or not and the respondent numbers were quite small, there was a 17% increase in the activity limitation days between those with DED and those without DED. Knowing that diabetes-related vision loss is preventable, addressing barriers to eye screening is an important policy issue. While most respondents had received an eye exam, which is understandable considering the purposeful sample, there remained many barriers, beyond one's personal control, primarily those associated with clinical capacities resulting in long wait times for appointments as noted by both patients and providers.

The top patient characteristics influencing the referral process for eye care across providers, including ophthalmologists, were a patient's age, the presence of comorbidities such as hypertension, a patient's diabetes duration, high glucose levels, and a patient's ability to adhere to recommendations.

Although small in numbers, ophthalmologists reported that the greatest challenges for improving patient outcomes in DED were reimbursement restrictions on approved therapy (25%, n=2) and the complex referral pathways (25%, n=2).

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 screening.

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

# **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/
- <sup>3</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>4</sup> International Diabetes Federation. (2015). *IDF Diabetes Atlas*. Accessed from: http:// www.diabetesatlas.org/
- <sup>5</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

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

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

#### Table 1.1

Survey Information	Number of Respondents (%)
All valid respondents [1]	82 (100.0%)
Respondents aged 18 or over	81 (98.8%)
Respondents with diabetes	79 (96.3%)

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

#### Table 1.2

Survey Information	Number of Respondents (%)
All valid respondents	82 (100.0%)
Included in Diabetic Analysis Set	79 (96.3%)
Excluded from Diabetic Analysis Set	3 (3.7%)
Reasons for exclusion from diabetic analysis set	
Under 18 years of age	1
Not diagnosed with diabetes	1
Missing information on diabetes diagnosis	1

#### Table 1.3

Survey Information	Number of Respondents (%)
Diabetic Analysis Set	79 (100.0%)
World Bank Income Group: High Income	79 (100.0%)
Persons with diabetic eye disease (DED)	6 (7.6%)
Persons with diabetic macular edema (DME)	2 (2.5%)
Persons with Type I diabetes	11 (13.9%)
Persons with Type II diabetes	65 (82.3%)
Persons not seeing health care professional for diabetes	5 (6.3%)
Persons seeing health care professional for diabetes	74 (93.7%)
Persons with eye disease & not received treatment	3 (3.8%)
Persons with eye disease & received treatment	5 (6.3%)



Question	Response	Number of Respondents (%)
With which type of diabetes have you been diagnosed?	Туре І	11 (13.9)
	Туре II	65 (82.3)
	Don't know/Not sure	3 (3.8)
	Total Valid Response	79 (100.0)

#### Table 2.2

Question	Response	Number of Respondents (%)
When was your diabetes diagnosed?	Within the last year	5 (6.3)
	1 - 5 years ago	30 (38.0)
	6 - 10 years ago	19 (24.1)
	11 - 15 years ago	13 (16.5)
	16 - 20 years ago	4 (5.1)
	21 years ago or longer	7 (8.9)
	Don't know/Not sure	1 (1.3)
	Total Valid Response	79 (100.0)

#### Table 2.3.1

Question	Response	Number of Respondents (%)
Do you see a health care professional for your diabetes?	Yes	74 (93.7)
	No	5 (6.3)
	Total Valid Response	79 (100.0)
What kind of health care professional?	General/Family Doctor	20 (27.4)
	Nurse	32 (43.8)
	Diabetes Specialist	18 (24.7)
	Other	3 (4.1)
	Total Valid Response	73 (100.0)
	Total missing	6

Table	2.3.2
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Type of health care professional	Times per year seen for diabetes	Value
General/Family Doctor	Total valid numeric response (n)	18
	Mean	3.8
	SD	1.1
	Median	4.0
	Min	1
	Max	6
	Don't know/Not sure	2
Nurse	Total valid numeric response (n)	30
	Mean	3.6
	SD	0.9
	Median	4.0
	Min	1
	Max	6
	Don't know/Not sure	1
	Total missing	1
Diabetes Specialist	Total valid numeric response (n)	15
	Mean	3.0
	SD	1.2
	Median	3.0
	Min	1
	Max	6
	Don't know/Not sure	2
	Total missing	1
Other	Total valid numeric response (n)	3
	Mean	3.3
	SD	1.2
	Median	4.0
	Min	2
	Мах	4



Question	Response	Number of Respondents (%)
How have you received information about diabetes?	Doctor or nurse	71 (92.2%)
	Health educator	9 (11.7%)
	Nutritionist or dietitian	25 (32.5%)
	Diabetes organization or other health organization	20 (26.0%)
	Family/Friends/Neighbors	6 (7.8%)
	TV/Radio/Newspaper/Magazines	4 (5.2%)
	Internet	26 (33.8%)
	Social media (e.g. Facebook, Twitter, blogs)	4 (5.2%)
	Pharmacist	12 (15.6%)
	Total Valid Response	77 (100.0%)
	Total missing	2

#### Table 2.5

Question	Response	Number of Respondents (%)
How do you manage your diabetes?	Diet	33 (42.9%)
	Oral medicine	49 (63.6%)
	Exercise	32 (41.6%)
	Insulin	33 (42.9%)
	Natural/Herbal medicine	3 (3.9%)
	None of the above	2 (2.6%)
	Total Valid Response	77 (100.0%)
	Total missing	2

#### Table 2.6

Question	Response	Number of Respondents (%)
Are you currently enrolled in a diabetes patient management support programme?	Yes	17 (22.1)
	No	60 (77.9)
	Total Valid Response	77 (100.0)

Question	Response	Number of Respondents (%)
	Total missing	2
Who sponsors the programme?	Hospital support program	4 (23.5)
	Clinic support program	1 (5.9)
	Patient organization support program	3 (17.6)
	Don't know/Not sure	9 (52.9)
	Total Valid Response	17 (100.0)
	Total missing	62
Does the programme include education on the importance of screening for diabetic eye complications?	Yes	17 (100.0)
	Total Valid Response	17 (100.0)
	Total missing	62

Test	Response	Number of Respondents (%)
Have you ever had the following tests in a doctors office of clinic? And if yes, how long ago		
Blood glucose test	Yes	73 (97.3%)
	Less than 6 months	65 (86.7%)
	6 - 12 months	6 (8.0%)
	Greater than 12 months	2 (2.7%)
	Total valid response	73 (97.3%)
	Total missing	6
	No	2 (2.7%)
	Total valid response	75 (100.0%)
	Total missing	4
Urine check	Yes	72 (97.3%)
	Less than 6 months	51 (68.9%)



Test	Response	Number of Respondents (%)
Have you ever had the following tests in a doctors office of clinic? And if yes, how long ago		
	6 - 12 months	18 (24.3%)
	Greater than 12 months	3 (4.1%)
	Total valid response	72 (97.3%)
	Total missing	7
	No	1 (1.4%)
	Don't know/Not sure	1 (1.4%)
	Total valid response	74 (100.0%)
	Total missing	5
Weight check	Yes	71 (94.7%)
	Less than 6 months	62 (82.7%)
	6 - 12 months	6 (8.0%)
	Greater than 12 months	2 (2.7%)
	Total valid response	70 (93.3%)
	Total missing	9
	No	4 (5.3%)
	Total valid response	75 (100.0%)
	Total missing	4
Blood pressure check	Yes	74 (100.0%)
	Less than 6 months	64 (86.5%)
	6 - 12 months	8 (10.8%)
	Greater than 12 months	2 (2.7%)
	Total valid response	74 (100.0%)
	Total missing	5
	Total valid	74 (100.0%)

Test	Response	Number of Respondents (%)
Have you ever had the following tests in a doctors office of clinic? And if yes, how long ago		
	response	
	Total missing	5
Foot check	Yes	69 (92.0%)
	Less than 6 months	43 (57.3%)
	6 - 12 months	20 (26.7%)
	Greater than 12 months	5 (6.7%)
	Total valid response	68 (90.7%)
	Total missing	11
	No	6 (8.0%)
	Total valid response	75 (100.0%)
	Total missing	4
Eye check	Yes	69 (92.0%)
	Less than 6 months	26 (34.7%)
	6 - 12 months	35 (46.7%)
	Greater than 12 months	8 (10.7%)
	Total valid response	69 (92.0%)
	Total missing	10
	No	6 (8.0%)
	Total valid response	75 (100.0%)
	Total missing	4

Question	Response	Number of Respondents (%)
How well do you think your diabetes is controlled?	Very well	20 (26.7%)



Question	Response	Number of Respondents (%)
	Well	42 (56.0%)
	Not very well	9 (12.0%)
	Not well at all	2 (2.7%)
	Don't know/Not sure	2 (2.7%)
	Total Valid Response	75 (100.0%)
	Total missing	4

Question	Response	Number of Respondents (%)
What are the main challenges you face in controlling your diabetes?	High cost of care	21 (28.0%)
	Travel to my regular doctor or specialist is difficult	14 (18.7%)
	Long wait time for an appointment to see my doctor or specialist	5 (6.7%)
	Health services needed are not available	1 (1.3%)
	Don't know enough about diabetes	4 (5.3%)
	Too hard to eat the right things	16 (21.3%)
	Too many other things to do	9 (12.0%)
	Stigma or discrimination because of diabetes	6 (8.0%)
	Don't want to think about having diabetes	22 (29.3%)
	Other	8 (10.7%)
	Total Valid Response	75 (100.0%)
	Total missing	4

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	15 (20.0%)

Question	Response	Number of Respondents (%)
	Support groups	3 (4.0%)
	Support from family or friends	11 (14.7%)
	Health education and information	18 (24.0%)
	Mobile services (services that travel to or near your home)	1 (1.3%)
	Coordination of healthcare and services by a professional	17 (22.7%)
	Emergency helpline	4 (5.3%)
	Other	6 (8.0%)
	None	29 (38.7%)
	Total Valid Response	75 (100.0%)
	Total missing	4

Question	Response	Number of Respondents (%)
What complications (or problems), to your knowledge, arise from diabetes?	Amputation	50 (66.7%)
	Foot ulcers	37 (49.3%)
	Increased risk of broken bones or fractures	7 (9.3%)
	Loss of feeling in hands or toes (neuropathy)	45 (60.0%)
	Vision loss	46 (61.3%)
	Irritable bowel disease	10 (13.3%)
	Kidney disease	33 (44.0%)
	Cardiovascular disease/Stroke	43 (57.3%)
	Other	1 (1.3%)
	Don't know/Not sure	4 (5.3%)
	None	6 (8.0%)
	Total Valid Response	75 (100.0%)
	Total missing	4



Question	Response	Number of Respondents (%)
Which complication of diabetes are you most concerned about?	Amputation	7 (9.3)
	Foot ulcers	1 (1.3)
	Increased risk of broken bones or fractures	2 (2.7)
	Loss of feeling in hands or toes (neuropathy)	8 (10.7)
	Vision loss	14 (18.7)
	Irritable bowel disease	1 (1.3)
	Kidney disease	3 (4.0)
	Cardiovascular disease/Stroke	13 (17.3)
	Don't know/Not sure	9 (12.0)
	None	17 (22.7)
	Total Valid Response	75 (100.0)
	Total missing	4

Question	Response	Number of Respondents (%)
Which of the following complications of diabetes do you have?	Amputation	2 (2.7%)
	Foot ulcers	4 (5.3%)
	Broken bones or fractures	1 (1.3%)
	Loss of feeling in hands or toes (neuropathy)	21 (28.0%)
	Vision loss	7 (9.3%)
	Irritable bowel disease	6 (8.0%)
	Kidney disease	5 (6.7%)
	Cardiovascular disease/Stroke	11 (14.7%)
	Other	1 (1.3%)
	Don't know/Not sure	6 (8.0%)
	None	37 (49.3%)
	Total Valid Response	75 (100.0%)
	Total missing	4

Question	Response	Number of Respondents (%)
How often do you discuss the possibility of eye complications with your health care professional?	Every visit	7 (9.3%)
	Multiple times per year	10 (13.3%)
	Once per year	36 (48.0%)
	Only when symptoms arise	13 (17.3%)
	Never	9 (12.0%)
	Total Valid Response	75 (100.0%)
	Total missing	4

## 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	32 (42.7%)
	I do what I can to prevent vision problems (e.g. get routine screenings, visit specialists)	35 (46.7%)
	I do not make any special effort to prevent vision problems	16 (21.3%)
	Total Valid Response	75 (100.0%)
	Total missing	4

### Table 2.16

Question	Response	Number of Respondents (%)
What type of health insurance do you have?	Public	22 (29.3)
	Public - Private	52 (69.3)
	None	1 (1.3)
	Total Valid Response	75 (100.0)
	Total missing	4



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	19 (25.3)
	Insurance pays total cost	51 (68.0)
	Insurance and out-of- pocket/cash (e.g. co-pays)	2 (2.7)
	Out-of-pocket only (pay cash for all care)	1 (1.3)
	Do not use service	2 (2.7)
	Total Valid Response	75 (100.0)
	Total missing	4
Specialist medical visits (e.g. eye doctor, gynecologist, urologist)	Care is free	4 (5.4)
	Insurance pays total cost	56 (75.7)
	Insurance and out-of- pocket/cash (e.g. co-pays)	12 (16.2)
	Out-of-pocket only (pay cash for all care)	1 (1.4)
	Do not use service	1 (1.4)
	Total Valid Response	74 (100.0)
	Total missing	5
Medicines	Care is free	1 (1.4)
	Insurance pays total cost	40 (54.8)
	Insurance and out-of- pocket/cash (e.g. co-pays)	29 (39.7)
	Out-of-pocket only (pay cash for all care)	2 (2.7)
	Do not use service	1 (1.4)
	Total Valid Response	73 (100.0)
	Total missing	6
Medical supplies (e.g. blood glucose meter/strips)	Care is free	6 (8.1)
	Insurance pays total cost	28 (37.8)
	Insurance and out-of- pocket/cash (e.g. co-pays)	9 (12.2)
	Out-of-pocket only (pay	14 (18.9)

Most often, how do you pay for the following types of medical care and services?cash for all care)Do not use service15 (20.3)Do n't know/Not Sure2 (2.7)Total Valid Response74 (100.0)Total missing5ProceduresCare is free6 (8.0)Insurance pays total cost24 (32.0)Insurance and out-of- pocket/cash (e.g. co-pays)13 (17.3)Out-of-pocket only (pay cash for all care)2 (2.7)Don't know/Not Sure17 (22.7)Don't know/Not Sure17 (22.7)Don't know/Not Sure13 (17.3)Total missing4Tests/screeningsCare is free6 (8.2)Tests/screeningsCare is free6 (8.2)Insurance and out-of- pocket/cash (e.g. co-pays)38 (52.1)Insurance and out-of- pocket/cash (e.g. co-pays)14 (19.2)Care is free6 (8.2)Insurance and out-of- pocket/cash (e.g. co-pays)2 (2.7)Care is free5 (8.2)Insurance and out-of- pocket/cash (e.g. co-pays)2 (2.7)Do not use service7 (9.6)Don't know/Not Sure6 (8.2)Total Valid Response73 (100.0)Total Valid Response73 (100.0) <tr< th=""><th>Question</th><th>Response</th><th>Number of Respondents (%)</th></tr<>	Question	Response	Number of Respondents (%)
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cash for all care)Do not use service20 (27.0)			5 (6.8)
			1 (1.4)
Don't know/Not Sure 12 (16.2)		Do not use service	20 (27.0)
		Don't know/Not Sure	12 (16.2)



Question	Response	Number of Respondents (%)
Most often, how do you pay for the following types of medical care and services?		
	Total Valid Response	74 (100.0)
	Total missing	5
Counseling	Care is free	8 (10.8)
	Insurance pays total cost	37 (50.0)
	Insurance and out-of- pocket/cash (e.g. co-pays)	9 (12.2)
	Do not use service	13 (17.6)
	Don't know/Not Sure	7 (9.5)
	Total Valid Response	74 (100.0)
	Total missing	5

Question	Response	Number of Respondents (%)
Are you aware of any government sponsored screening programs for diabetic eye disease (diabetic retinopathy)?	Yes	18 (24.0%)
	No	57 (76.0%)
	Total valid response	75 (100.0%)
	Total missing	4

Question	Response	Number of Respondents (%)
Have you ever had an eye exam for diabetic eye disease?	Yes	63 (82.9%)
	No	13 (17.1%)
	Total valid response	76 (100.0%)
	Total missing	3
How long ago was your last eye exam?	Within the last year	46 (73.0%)
	More than 1 year ago but less than 2 years	14 (22.2%)
	More than 2 years ago but less than 3 years	2 (3.2%)

Question	Response	Number of Respondents (%)
	Don't know/Not sure	1 (1.6%)
	Total valid response	63 (100.0%)
	Total missing	16
Who did the last exam?	Eye doctor/Eye clinic	51 (81.0%)
	Other	12 (19.0%)
	Total valid response	63 (100.0%)
	Total missing	16

Question	Response	Number of Respondents (%)
Have you ever had a dilated eye exam, where your eyes are examined after eye drops?	Yes	63 (86.3%)
	No	9 (12.3%)
	Don't know/Not sure	1 (1.4%)
	Total valid response	73 (100.0%)
	Total missing	6

## Table 3.4

Question	Response	Number of Respondents (%)
Based on what you know, how often should you get your eyes examined for diabetic eye disease?	Once a year	49 (67.1%)
	Every two years	19 (26.0%)
	Less often than every two years	1 (1.4%)
	Never	2 (2.7%)
	Don't know/Not sure	2 (2.7%)
	Total valid response	73 (100.0%)
	Total missing	6



Question	Response	Number of Respondents (%)
For you, what are the biggest barriers to eye exams?	They are expensive	6 (8.6%)
	Long wait time for appointment	10 (14.3%)
	Long wait time on the day of the visit	6 (8.6%)
	Recommended treatments for eye problems are not available	2 (2.9%)
	Don't know much about my condition	7 (10.0%)
	Fear of treatment/results	5 (7.1%)
	Limited access to diabetes specialists	2 (2.9%)
	I'm not likely to have eye complications	5 (7.1%)
	Eye exams are not important	1 (1.4%)
	Too many other things to do or worry about	5 (7.1%)
	Other	36 (51.4%)
	Total valid response	70 (100.0%)
	Total missing	9

Question	Response	Number of Respondents (%)
Have you been diagnosed with diabetic eye disease?	Yes	8 (10.5%)
	No	68 (89.5%)
	Total valid response	76 (100.0%)
	Total missing	3
Has your diabetic eye disease affected your vision?	Yes, slightly	6 (75.0%)
	Yes, significantly	2 (25.0%)
	Total valid response	8 (100.0%)
	Total missing	71
Have vision issues caused you to have difficulty with any of the following?	Household responsibilities, such as cooking or cleaning	1 (14.3%)
	Social interactions with family/friends	2 (28.6%)
	Leisure activities/exercise	1 (14.3%)

Question	Response	Number of Respondents (%)
	Work or keeping a job	3 (42.9%)
	Managing my diabetes	4 (57.1%)
	None	1 (14.3%)
	Driving (a car/vehicle)	2 (28.6%)
	Total valid response	7 (100.0%)
	Total missing	72

Question	Response	Number of Respondents (%)
Have you had any treatment for diabetic eye disease?	Yes	5 (62.5%)
	No	3 (37.5%)
	Total valid response	8 (100.0%)
	Total missing	71
What treatment did you receive?	Laser	3 (60.0%)
	Injection in the eye (Anti- VEGF)	1 (20.0%)
	Other	1 (20.0%)
	Total valid response	5 (100.0%)
	Total missing	74
Did you complete the treatment?	Yes	3 (60.0%)
	No	1 (20.0%)
	Still receiving treatment	1 (20.0%)
	Total valid response	5 (100.0%)
	Total missing	74
Do you feel that the treatment worked?	Yes, and vision improved	1 (25.0%)
	Yes, but vision stayed the same	2 (50.0%)
	Still waiting to know	1 (25.0%)
	Total valid response	4 (100.0%)
	Total missing	75
What is/are the reason(s) that you did not complete the treatment?	I was fearful (scared) of treatment	1 (100.0%)



Question	Response	Number of Respondents (%)
	Total valid response	1 (100.0%)
	Total missing	78
What are the reason(s) that you have not had treatment for diabetic eye disease?	My doctor did not recommend any treatment	1 (50.0%)
	Treatment would not be effective	1 (50.0%)
	Treatment is not accessible	1 (50.0%)
	Total valid response	2 (100.0%)
	Total missing	77

Question	Response	Number of Respondents (%)
Have you been diagnosed with diabetic macular edema?	Yes	2 (2.7%)
	No	52 (69.3%)
	Don't know/Not sure	21 (28.0%)
	Total valid response	75 (100.0%)
	Total missing	4
If Yes, which of the following would you prefer	Treatment to prevent further vision loss	1 (50.0%)
	Only treatment when vision loss has occurred	1 (50.0%)
	Total valid response	2 (100.0%)
	Total missing	77

Question	Response	Number of Respondents (%)
Have you received information about diabetic retinopathy or diabetic macular edema from any of the following sources?	Doctor/Nurse	20 (26.7%)
	Health educator	3 (4.0%)
	Diabetes organization or other health organization	7 (9.3%)

Question	Response	Number of Respondents (%)
	TV/Radio/Newspaper/Magazines	2 (2.7%)
	Internet	3 (4.0%)
	None of the above	49 (65.3%)
	Total valid response	75 (100.0%)
	Total missing	4

### Table 4.1

Question	Response	Number of Respondents (%)
What is your gender?	Female	30 (40.5)
	Male	44 (59.5)
	Total Valid Response	74 (100.0)
	Total missing	5
Please indicate your age	18 - 29	6 (7.6)
	40 - 49	14 (17.7)
	50 - 59	24 (30.4)
	60 - 69	27 (34.2)
	70 - 79	6 (7.6)
	80 - 89	2 (2.5)
	Total Valid Response	79 (100.0)

### Table 4.2

Question	Response	Number of Respondents (%)
Where do you live?	Urban setting	42 (56.0)
	Non-urban setting	33 (44.0)
	Total Valid Response	75 (100.0)
	Total missing	4

## Table 4.3

Question	Response	Number of Respondents (%)
What is the highest level of education you completed?	Primary school	6 (8.0)
	Secondary school	39 (52.0)



Question	Response	Number of Respondents (%)
	College/University	28 (37.3)
	Graduate or post- graduate	2 (2.7)
	Total valid response	75 (100.0)
	Total missing	4

#### Table 4.4

Question	Response	Number of Respondents (%)
Are you currently working?	Working for pay	27 (36.0)
	Working without pay at home (e.g. housework, farming)	2 (2.7)
	Volunteering	1 (1.3)
	Retired	22 (29.3)
	Student	1 (1.3)
	Not working	22 (29.3)
	Total Valid Response	75 (100.0)
	Total missing	4

## Table 4.5

Question	Response	Number of Respondents (%)
Do you receive assistance from the government?	Income assistance	8 (10.7%)
	Medical assistance	5 (6.7%)
	Food assistance	2 (2.7%)
	Housing assistance	2 (2.7%)
	Pension assistance	4 (5.3%)
	None of the above	57 (76.0%)
	Total valid response	75 (100.0%)
	Total missing	4

Question	Response	Number of Respondents (%)
Did you have trouble paying for food at anytime during the past year?	Yes	33 (44.6)
	No	41 (55.4)
	Total Valid Response	74 (100.0)
	Total missing	5

## 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	8 (10.7)
	Ethnicity	1 (1.3)
	Income	5 (6.7)
	Place where you live	3 (4.0)
	Tribal affiliation	1 (1.3)
	None of the above	63 (84.0)
	Total valid response	75 (100.0)
	Total missing	4

### Table 4.8

Question	Response	Number of Respondents (%)
Which of the following do you worry about most?	Food	1 (1.3)
	Housing	3 (4.0)
	Money	24 (32.0)
	Health	26 (34.7)
	Family	4 (5.3)
	None of the above	17 (22.7)
	Total Valid Response	75 (100.0)
	Total missing	4



# Table 5.1

Question	Response	Number of Respondents (%)
In general, would you say your health is:	Very good	6 (8.2%)
	Good	28 (38.4%)
	Total good health	34 (46.6%)
	Fair	26 (35.6%)
	Poor	13 (17.8%)
	Fair or poor health	39 (53.4%)
	Total valid response	73 (100.0%)
	Total missing	6

#### Table 5.2

Question	Response	Number of Respondents (%)
How many days during last 30 days was your physical health not good	Any unhealthy days	29 (46.8%)
	1-5 unhealthy days	8 (12.9%)
	6-10 unhealthy days	2 (3.2%)
	11-20 unhealthy days	7 (11.3%)
	21-30 unhealthy days	12 (19.4%)
	No unhealthy days	33 (53.2%)
	Total valid response	62 (100.0%)
	Total missing	17

### 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	23 (35.4%)
	1-5 unhealthy days	4 (6.2%)

Question	Response	Number of Respondents (%)
	6-10 unhealthy days	4 (6.2%)
	11-20 unhealthy days	7 (10.8%)
	21-30 unhealthy days	8 (12.3%)
	No unhealthy days	42 (64.6%)
	Total valid response	65 (100.0%)
	Total missing	14

## Table 5.3.2

Question	Response	Number of Respondents (%)
Unhealthy days (physically or mentally unhealthy, max 30)	Any unhealthy days	37 (58.7%)
	1-5 unhealthy days	8 (12.7%)
	6-10 unhealthy days	1 (1.6%)
	11-20 unhealthy days	10 (15.9%)
	21-30 unhealthy days	18 (28.6%)
	No unhealthy days	26 (41.3%)
	Total valid response	63 (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	21 (52.5%)
	1-5 unhealthy days	5 (12.5%)
	6-10 unhealthy days	5 (12.5%)



Question	Response	Number of Respondents (%)
	11-20 unhealthy days	5 (12.5%)
	21-30 unhealthy days	6 (15.0%)
	No unhealthy days	19 (47.5%)
	Total valid response	40 (100.0%)
	Total missing	39

## Table 5.5

Question	Response	Number of Respondents (%)
Are you limited in any way in any activities because of any impairment or health problem?	Yes	34 (48.6%)
	No	36 (51.4%)
	Total valid response	70 (100.0%)
	Total missing	9
Which impairment or health problem, if any, limits your activities?		
a) Arthritis/rheumatism	Yes	12 (35.3%)
	No	21 (61.8%)
	Don't know/Not sure	1 (2.9%)
	Total valid response	34 (100.0%)
	Total missing	45
b) Back or neck problem	Yes	26 (70.3%)
	No	11 (29.7%)
	Total valid response	37 (100.0%)
	Total missing	42
c) Fractures, bone/joint injury	Yes	7 (20.6%)
	No	26 (76.5%)
	Don't know/Not sure	1 (2.9%)

Question	Response	Number of Respondents (%)
	Total valid response	34 (100.0%)
	Total missing	45
d) Walking problem	Yes	27 (75.0%)
	No	8 (22.2%)
	Don't know/Not sure	1 (2.8%)
	Total valid response	36 (100.0%)
	Total missing	43
e) Lung/breathing problem	Yes	19 (51.4%)
	No	18 (48.6%)
	Total valid response	37 (100.0%)
	Total missing	42
f) Hearing problem	Yes	7 (20.6%)
	No	25 (73.5%)
g) Eye/vision problem	Don't know/Not sure	2 (5.9%)
	Total valid response	34 (100.0%)
	Total missing	45
	Yes	12 (35.3%)
	No	22 (64.7%)
	Total valid response	34 (100.0%)
	Total missing	45
h) Heart problem	Yes	7 (20.0%)
	No	26 (74.3%)
	Don't know/Not sure	2 (5.7%)
	Total valid response	35 (100.0%)
	Total missing	44
i) Stroke problem	Yes	2 (5.9%)
	No	32 (94.1%)



Question	Response	Number of Respondents (%)
	Total valid response	34 (100.0%)
	Total missing	45
j) Hypertension/high blood pressure	Yes	18 (50.0%)
	No	17 (47.2%)
	Don't know/Not sure	1 (2.8%)
	Total valid response	36 (100.0%)
	Total missing	43
k) Diabetes	Yes	33 (86.8%)
	No	5 (13.2%)
	Total valid response	38 (100.0%)
	Total missing	41
l) Cancer	Yes	2 (5.7%)
	No	32 (91.4%)
	Don't know/Not sure	1 (2.9%)
	Total valid response	35 (100.0%)
	Total missing	44
m) Mental or emotional health	Yes	14 (42.4%)
	No	16 (48.5%)
	Don't know/Not sure	3 (9.1%)
	Total valid response	33 (100.0%)
	Total missing	46

## PT 1.2

Analysis Sets	Number of Respondents (%)
All valid respondents	17 (100.0%)
Included in Provider Analysis Set (PAS)	17 (100.0%)

Analysis Sets	Number of Respondents (%)
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	17
Included in the Eye Care Professional Set (Eye Specialist)	13 (76.5%)
Excluded in the Eye Care Professional Set (Eye Specialist)	4 (23.5%)
Reasons for exclusion from Eye Care Professional Set:	
Missing required speciality	4
No valid (non-missing) response for the supplemental eye questionnaire	0

### PT 1.3

Subgroups	Number of Respondents (%)
Provider Analysis Set	17 (100.0%)
Primary Care Provider	0 (0.0%)
Diabetes Specialist Provider	1 (5.9%)
Eye Care Professional	13 (76.5%)
Ophthalmologist	13 (76.5%)

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

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

NB [4]: Ophthalmologist = General ophthalmologist or retinal specialist NB [5]: Note that providers may have selected more than one specialty

#### PT 1.4

Item	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
What is your specialty?	General primary care/Family practitioner	N/A	0 (0.0%)	0 (0.0%)	0 (0.0%)
	Diabetes specialist	N/A	1 (100.0%)	0 (0.0%)	1 (5.9%)
	General ophthalmologist	N/A	0 (0.0%)	10 (76.9%)	10 (58.8%)
	Optometrist	N/A	0 (0.0%)	0 (0.0%)	0 (0.0%)
	Retinal specialist	N/A	0 (0.0%)	4 (30.8%)	4 (23.5%)
	Nurse	N/A	0 (0.0%)	0 (0.0%)	2 (11.8%)
	Health educator	N/A	0 (0.0%)	0 (0.0%)	0 (0.0%)



Item	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	None of the above	N/A	0 (0.0%)	0 (0.0%)	1 (5.9%)
	Total valid response	0 (100.0%)	1 (100.0%)	13 (100.0%)	17 (100.0%)
	Total missing	0	0	0	0

## PT 1.5

Item	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
How long have you been practicing in this profession?	Total valid response (n)		1	13	17
	Mean	•	5.0	16.2	15.7
	SD			9.5	10.0
	Median		5.0	15.0	13.0
	Min.		5	2	2
	Max.	•	5	30	33
	Total missing	0	0	0	0

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
What is your main practice setting?	Diabetes clinic/practice	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	Eye clinic/practice	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	General medical clinic/practice	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	Hospital	0 (0.0%)	1 (100.0%)	13 (100.0%)	16 (94.1%)
	Other	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (5.9%)
	Total Valid Response	0 (0.0%)	1 (100.0%)	13 (100.0%)	17 (100.0%)
	Total missing	0	0	0	0

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Where is your main practice located?	Urban setting	0 (0.0%)	1 (100.0%)	12 (92.3%)	16 (94.1%)
	Non-urban setting	0 (0.0%)	0 (0.0%)	1 (7.7%)	1 (5.9%)
	Total Valid Response	0 (0.0%)	1 (100.0%)	13 (100.0%)	17 (100.0%)
	Total missing	0	0	0	0

# PT 2.3

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
In which sector is your main practice?	Government	0 (0.0%)	1 (100.0%)	5 (38.5%)	7 (41.2%)
	Private	0 (0.0%)	0 (0.0%)	1 (7.7%)	1 (5.9%)
	Non profit	0 (0.0%)	0 (0.0%)	3 (23.1%)	5 (29.4%)
	Combined/mixed	0 (0.0%)	0 (0.0%)	4 (30.8%)	4 (23.5%)
	Total Valid Response	0 (0.0%)	1 (100.0%)	13 (100.0%)	17 (100.0%)
	Non profit	0	0	0	0

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%)	13 (100.0%)	15 (88.2%)
	Yes, limited by age	0 (0.0%)	1 (100.0%)	0 (0.0%)	2 (11.8%)
	Total valid response	0	1 (100.0%)	13 (100.0%)	17 (100.0%)
	Total missing	0	0	0	0



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%)	1 (100.0%)	2 (16.7%)	5 (31.3%)
	More than 1 week but less than 1 month	0 (0.0%)	0 (0.0%)	3 (25.0%)	4 (25.0%)
	More than 1 month but less than 2 months	0 (0.0%)	0 (0.0%)	4 (33.3%)	4 (25.0%)
	More than 2 months but less than 3 months	0 (0.0%)	0 (0.0%)	3 (25.0%)	3 (18.8%)
	Total Valid Response	0 (0.0%)	1 (100.0%)	12 (100.0%)	16 (100.0%)
	Total missing	0	0	1	1

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	12	16
	Mean	N/A	20	134.6	105.3
	SD	N/A		73.7	82.1
	Median	N/A	20	122.5	110
	Min.	N/A	20	40	5
	Max.	N/A	20	300	300
	Total missing	0	0	1	1
What percentage of the patients in your main practice have diabetes [% patients]	Total valid response (n)	0	1	12	16
	Mean	N/A	50	19.6	30.6

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	SD	N/A	•	19	32.8
	Median	N/A	50	15	15
	Min.	N/A	50	5	5
	Max.	N/A	50	75	100
	Total missing	0	0	1	1

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
In your main practice, how do patients pay for the care and services that you provide?	Don't pay	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (6.3%)
	Pay out-of- pocket (full fees)	0 (0.0%)	1 (100.0%)	0 (0.0%)	1 (6.3%)
	Pay through insurance	0 (0.0%)	0 (0.0%)	10 (83.3%)	12 (75.0%)
	Patient pays some, insurance pays some	0 (0.0%)	0 (0.0%)	3 (25.0%)	3 (18.8%)
	Total valid response	0	1 (100.0%)	12 (100.0%)	16 (100.0%)
	Total missing	0	0	1	1

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
In addition to your main practice, do you work in another practice setting?	Yes			4 (33.3%)	4 (25.0%)
	No		1 (100.0%)	8 (66.7%)	12 (75.0%)



Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Total valid response		1 (100.0%)	12 (100.0%)	16 (100.0%)
	Total missing			1	1
In which other practice setting(s) do you work?	Hospital			2 (50.0%)	2 (50.0%)
	General medical clinic/practice	-		1 (25.0%)	1 (25.0%)
	Eye clinic/practice	-		3 (75.0%)	3 (75.0%)
	Total valid response			4 (100.0%)	4 (100.0%)
	Total missing		1	9	13
In which sector(s) is(are) the practice(s)?	Government			1 (25.0%)	1 (25.0%)
	Private	-		1 (25.0%)	1 (25.0%)
	Combined/mixed	•		2 (50.0%)	2 (50.0%)
	Total valid response	-		4 (100.0%)	4 (100.0%)
	Total missing		1	9	13
Is there a major difference between your practices with respect to how diabetic eye disease is screened and managed?	Yes			1 (25.0%)	1 (25.0%)
	No			3 (75.0%)	3 (75.0%)
	Total valid response	1		4 (100.0%)	4 (100.0%)
	Total missing	1	1	9	13

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%)	6 (66.7%)
		Total valid numeric response (n)		1 (100.0%)	3 (50.0%)	5 (55.6%)
		Mean		200.0	3.7	42.6
		SD			0.6	88.0
		Median		200.0	4.0	4.0
		Min	•	200	3	2
		Max		200	4	200
		Total missing	-	0	10	12
	No		1		3 (50.0%)	3 (33.3%)
	Total valid response			1 (100.0%)	6 (100.0%)	9 (100.0%)
	Total missing			L	7	8
HbA1c	Yes			1 (100.0%)	4 (57.1%)	7 (70.0%)
		Total valid numeric response (n)		1 (100.0%)	4 (57.1%)	6 (60.0%)
		Mean		4.0	3.8	3.5
		SD			0.5	0.8
		Median		4.0	4.0	4.0
		Min		4	3	2
		Max		4	4	4
		Total missing	-	0	9	11
	No		J	L	3 (42.9%)	3 (30.0%)
	Total valid response	1		1 (100.0%)	7 (100.0%)	10 (100.0%)
	Total	1		L	6	7



Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	missing					
Urine check	Yes			1 (100.0%)	3 (50.0%)	6 (66.7%)
		Total valid numeric response (n)		1 (100.0%)	3 (50.0%)	5 (55.6%)
		Mean		200.0	2.3	41.6
		SD	-		1.5	88.6
		Median		200.0	2.0	2.0
		Min	-	200	1	1
		Max	-	200	4	200
		Total missing		0	10	12
	No		1		3 (50.0%)	3 (33.3%)
	Total valid response			1 (100.0%)	6 (100.0%)	9 (100.0%)
	Total missing	-		L	7	8
Weight check	Yes	-		1 (100.0%)	3 (50.0%)	6 (66.7%)
	1	Total valid numeric response (n)		1 (100.0%)	3 (50.0%)	5 (55.6%)
		Mean	-	4.0	2.0	2.2
		SD	-		1.7	1.6
		Median	-	4.0	1.0	1.0
		Min	1	4	1	1
		Max	1	4	4	4
		Total missing		0	10	12
	No		1	L	3 (50.0%)	3 (33.3%)
	Total valid response			1 (100.0%)	6 (100.0%)	9 (100.0%)

Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Total missing				7	8
Blood pressure check	Yes			1 (100.0%)	4 (57.1%)	7 (70.0%)
		Total valid numeric response (n)		1 (100.0%)	4 (57.1%)	6 (60.0%)
		Mean		0.0	2.0	1.7
		SD			1.4	1.4
		Median		0.0	1.5	1.5
		Min	•	0	1	0
		Max		0	4	4
		Total missing		0	9	11
	No		1	L	3 (42.9%)	3 (30.0%)
	Total valid response	-		1 (100.0%)	7 (100.0%)	10 (100.0%)
	Total missing				6	7
Foot check	Yes			1 (100.0%)	3 (50.0%)	6 (66.7%)
		Total valid numeric response (n)		1 (100.0%)	3 (50.0%)	5 (55.6%)
		Mean		1.0	2.3	1.8
		SD			1.5	1.3
		Median		1.0	2.0	1.0
		Min		1	1	1
		Max		1	4	4
		Total missing		0	10	12
	No		J	L	3 (50.0%)	3 (33.3%)
	Total valid			1 (100.0%)	6 (100.0%)	9 (100.0%)



Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	response					
	Total missing				7	8
Eye examination - Un-dilated	Yes			1 (100.0%)	5 (55.6%)	7 (58.3%)
		Total valid numeric response (n)		1 (100.0%)	5 (55.6%)	6 (50.0%)
		Mean		1.0	1.0	1.0
		SD			0.7	0.6
		Median		1.0	1.0	1.0
		Min		1	0	0
		Max		1	2	2
		Total missing		0	8	11
	No		1		4 (44.4%)	5 (41.7%)
	Total valid response	-		1 (100.0%)	9 (100.0%)	12 (100.0%)
	Total missing			L	4	5
Eye examination - Optical Coherence Tomography	Yes				9 (90.0%)	10 (83.3%)
	1	Total valid numeric response (n)		0 (0.0%)	9 (90.0%)	9 (75.0%)
		Mean			0.9	0.9
		SD			0.6	0.6
		Median			1.0	1.0
		Min			0	0
		Max			2	2
	_	Total missing		1	4	8

Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	No			1 (100.0%)	1 (10.0%)	2 (16.7%)
	Total valid response			1 (100.0%)	10 (100.0%)	12 (100.0%)
	Total missing				3	5
Eye examination - Fundoscopy	Yes			1 (100.0%)	11 (100.0%)	14 (100.0%)
	1	Total valid numeric response (n)		1 (100.0%)	11 (100.0%)	13 (92.9%)
		Mean		1.0	1.1	1.1
		SD			0.3	0.3
		Median		1.0	1.0	1.0
		Min	•	1	1	1
		Max	•	1	2	2
		Total missing		0	2	4
	Total valid response		1	1 (100.0%)	11 (100.0%)	14 (100.0%)
	Total missing				2	3
Eye examination - Fluorescein Angiography	Yes				9 (90.0%)	10 (83.3%)
	1	Total valid numeric response (n)		0 (0.0%)	7 (70.0%)	7 (58.3%)
		Mean			0.1	0.1
		SD	1		0.4	0.4
		Median	1		0.0	0.0
		Min	1		0	0
		Max	1		1	1
		Total		1	6	10



Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
		missing				
	No		1	1 (100.0%)	1 (10.0%)	2 (16.7%)
	Total valid response			1 (100.0%)	10 (100.0%)	12 (100.0%)
	Total missing	•			3	5
Eye examination - Lipid check	Yes			1 (100.0%)	2 (33.3%)	3 (37.5%)
	1	Total valid numeric response (n)		1 (100.0%)	2 (33.3%)	3 (37.5%)
		Mean		1.0	1.0	1.0
		SD			0.0	0.0
		Median		1.0	1.0	1.0
		Min		1	1	1
		Max		1	1	1
		Total missing	-	0	11	14
	No		J	L	4 (66.7%)	5 (62.5%)
	Total valid response			1 (100.0%)	6 (100.0%)	8 (100.0%)
	Total missing				7	9

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%)	1 (100.0%)	8 (66.7%)	10 (71.4%)

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Diet/nutrition	0 (0.0%)	1 (100.0%)	3 (25.0%)	5 (35.7%)
	Exercise/physical activity	0 (0.0%)	1 (100.0%)	3 (25.0%)	5 (35.7%)
	Medicines	0 (0.0%)	1 (100.0%)	4 (33.3%)	6 (42.9%)
	Foot care and inspection	0 (0.0%)	0 (0.0%)	1 (8.3%)	1 (7.1%)
	Blood pressure	0 (0.0%)	0 (0.0%)	7 (58.3%)	7 (50.0%)
	Eye care and exams	0 (0.0%)	0 (0.0%)	11 (91.7%)	11 (78.6%)
	Lipid check	0 (0.0%)	0 (0.0%)	1 (8.3%)	1 (7.1%)
	None of the above	0 (0.0%)	0 (0.0%)	1 (8.3%)	1 (7.1%)
	Total valid response	0	1 (100.0%)	12 (100.0%)	14 (100.0%)
	Total missing	0	0	1	3

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%)	8 (66.7%)	8 (57.1%)
	Yes, but information on eye complications is not sufficient	0 (0.0%)	0 (0.0%)	2 (16.7%)	3 (21.4%)
	Yes, but no information on eye complications is included	0 (0.0%)	0 (0.0%)	1 (8.3%)	1 (7.1%)
	No written information is available for patients	0 (0.0%)	1 (100.0%)	0 (0.0%)	1 (7.1%)



Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Don't know/Not sure	0 (0.0%)	0 (0.0%)	1 (8.3%)	1 (7.1%)
	Total Valid Response	0 (0.0%)	1 (100.0%)	12 (100.0%)	14 (100.0%)
	Total missing	0	0	1	3

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%)	6 (50.0%)	7 (50.0%)
	Yes, available but not used by staff	0 (0.0%)	0 (0.0%)	1 (8.3%)	1 (7.1%)
	Not available	0 (0.0%)	1 (100.0%)	4 (33.3%)	5 (35.7%)
	Don't know/Not sure	0 (0.0%)	0 (0.0%)	1 (8.3%)	1 (7.1%)
	Total Valid Response	0 (0.0%)	1 (100.0%)	12 (100.0%)	14 (100.0%)
	Total missing	0	0	1	3

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%)	9 (75.0%)	9 (64.3%)

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Not available	0 (0.0%)	1 (100.0%)	2 (16.7%)	4 (28.6%)
	Don't know/Not sure	0 (0.0%)	0 (0.0%)	1 (8.3%)	1 (7.1%)
	Total Valid Response	0 (0.0%)	1 (100.0%)	12 (100.0%)	14 (100.0%)
	Total missing	0	0	1	3

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 (0.0%)	5 (41.7%)	6 (42.9%)
	Mean			5.0	5.0
	SD			0.0	0.0
	Median			5.0	5.0
	Min			5	5
	Max			5	5
	After a predetermined age (numeric response) (n)		0 (0.0%)	0 (0.0%)	0 (0.0%)
	Mean			•	
	SD				
	Median				
	Min				
	Max				
	As soon as they are diagnosed		1 (100.0%)	5 (41.7%)	6 (42.9%)
	When a patient			1 (8.3%)	1 (7.1%)



Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	reports eye/vision problems				
	No standard practice, timing varies case by case			1 (8.3%)	1 (7.1%)
	Total valid response		1 (100.0%)	12 (100.0%)	14 (100.0%)
	Total missing	-	L	1	3
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 (0.0%)
	Mean				·
	SD				
	Median	-			
	Min	-			
	Max	-			
	After a predetermined age (numeric response) (n)		0 (0.0%)	0 (0.0%)	0 (0.0%)
	Mean				
	SD				
	Median				
	Min				
	Max	1			
	As soon as they are diagnosed	1	1 (100.0%)	11 (91.7%)	13 (92.9%)
	When a patient reports eye/vision problems			1 (8.3%)	1 (7.1%)
	Total valid response		1 (100.0%)	12 (100.0%)	14 (100.0%)
	Total missing	1		1	3

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%)	1 (100.0%)	4 (33.3%)	6 (42.9%)
	Every two years	0 (0.0%)	0 (0.0%)	8 (66.7%)	8 (57.1%)
	Total Valid Response	0 (0.0%)	1 (100.0%)	12 (100.0%)	14 (100.0%)
	Total missing	0	0	1	3

### PT 2.16

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Do you screen patients for DR?	Yes		1 (100.0%)	12 (100.0%)	14 (100.0%)
	Total valid response		1 (100.0%)	12 (100.0%)	14 (100.0%)
	Total missing			1	3
Where do you screen patients?	In clinic		1 (100.0%)	9 (81.8%)	10 (76.9%)
	Outreach			1 (9.1%)	1 (7.7%)
	Other			3 (27.3%)	4 (30.8%)
	Total valid response		1 (100.0%)	11 (100.0%)	13 (100.0%)
	Total missing			2	4

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
What patient characteristics influence your vision care and/or	Diabetes duration	0 (0.0%)	0 (0.0%)	7 (58.3%)	8 (57.1%)



Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
vision referrals?					
	Patient's age	0 (0.0%)	0 (0.0%)	8 (66.7%)	9 (64.3%)
	Patient's gender	0 (0.0%)	0 (0.0%)	1 (8.3%)	1 (7.1%)
	Presence of comorbidities such as hypertension, etc.	0 (0.0%)	0 (0.0%)	8 (66.7%)	9 (64.3%)
	High glucose levels	0 (0.0%)	0 (0.0%)	7 (58.3%)	8 (57.1%)
	Patient educational level	0 (0.0%)	0 (0.0%)	2 (16.7%)	2 (14.3%)
	Patient adherence to recommendations	0 (0.0%)	0 (0.0%)	5 (41.7%)	5 (35.7%)
	None of the above	0 (0.0%)	0 (0.0%)	1 (8.3%)	1 (7.1%)
	Not applicable	0 (0.0%)	1 (100.0%)	3 (25.0%)	4 (28.6%)
	Total valid response	0	1 (100.0%)	12 (100.0%)	14 (100.0%)
	Total missing	0	0	1	3

# PT 2.18

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
What are the major barriers to optimizing eye health faced by patients with diabetes in your main practice?	Cost of care	0 (0.0%)	0 (0.0%)	1 (8.3%)	1 (7.1%)
	Long wait time for appointment	0 (0.0%)	0 (0.0%)	2 (16.7%)	2 (14.3%)
	Long wait time on the day of visit	0 (0.0%)	0 (0.0%)	1 (8.3%)	1 (7.1%)
	Referral process	0 (0.0%)	0 (0.0%)	1 (8.3%)	2 (14.3%)
	Patients fear of treatment/results	0 (0.0%)	0 (0.0%)	1 (8.3%)	1 (7.1%)

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Patients feel eye complications are unlikely	0 (0.0%)	0 (0.0%)	6 (50.0%)	6 (42.9%)
	Patients feel eye exams are not important	0 (0.0%)	0 (0.0%)	6 (50.0%)	6 (42.9%)
	Patients have competing responsibilities and priorities	0 (0.0%)	0 (0.0%)	2 (16.7%)	2 (14.3%)
	Clinic too small or lack necessary equipment/staff	0 (0.0%)	0 (0.0%)	1 (8.3%)	1 (7.1%)
	Other	0 (0.0%)	1 (100.0%)	4 (33.3%)	5 (35.7%)
	Total valid response	0	1 (100.0%)	12 (100.0%)	14 (100.0%)
	Total missing	0	0	1	3

# PT 2.19

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
In your main practice, are patients contacted with reminders for general follow-up appointments?	Yes	0 (0.0%)	1 (100.0%)	4 (33.3%)	6 (42.9%)
	No	0 (0.0%)	0 (0.0%)	8 (66.7%)	8 (57.1%)
	Total Valid Response	0 (0.0%)	1 (100.0%)	12 (100.0%)	14 (100.0%)
	Total missing	0	0	1	3

# PT 2.20

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Do you share relevant patient information with other health	Yes	0 (0.0%)	1 (100.0%)	11 (91.7%)	13



Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
care professionals involved in the patients care e.g. his or her general practitioner, ophthalmologist, podiastrist?					(92.9%)
	No	0 (0.0%)	0 (0.0%)	1 (8.3%)	1 (7.1%)
	Total Valid Response	0 (0.0%)	1 (100.0%)	12 (100.0%)	14 (100.0%)
	Total missing	0	0	1	3

### PT 3.1

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Please indicate your age:	30 - 39			3 (25.0%)	3 (21.4%)
	40 - 49		1 (100.0%)	2 (16.7%)	4 (28.6%)
	50 - 59			4 (33.3%)	4 (28.6%)
	60 - 69			3 (25.0%)	3 (21.4%)
	Total valid response	•	1 (100.0%)	12 (100.0%)	14 (100.0%)
	Total missing			1	3
What is your gender?	Female	•		5 (41.7%)	6 (42.9%)
	Male	•	1 (100.0%)	7 (58.3%)	8 (57.1%)
	Total valid response	•	1 (100.0%)	12 (100.0%)	14 (100.0%)
	Total missing			1	3
What is your highest level of education completed?	College/University			4 (33.3%)	5 (35.7%)
	Graduate or advanced degree (e.g. PhD, MD, etc)		1 (100.0%)	8 (66.7%)	9 (64.3%)

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Total valid response		1 (100.0%)	12 (100.0%)	14 (100.0%)
	Total missing			1	3

Question	Response	Ophthalmologist
What percentage of your patients have diabetic retinopathy	Total valid numeric response (n)	12
	Mean	17.4
	SD	27.3
	Median	5.0
	Min	1
	Max	75
	Total missing	1

# PT 4.2

Question	Response	Ophthalmologist
What percentage of your patients have diabetic macular edema?	Total valid numeric response (n)	12
	Mean	3.7
	SD	3.2
	Median	2.0
	Min	1
	Max	10
	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	1 (8.3%)
	More than 1 week but less than 1 month	3 (25.0%)
	More than 1 month but less than 2	4 (33.3%)



Question	Response	Ophthalmologist
	months	
	More than 2 months but less than 3 months	2 (16.7%)
	Other	2 (16.7%)
	Total Valid Response	12 (100.0%)
	Total missing	1

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	5 (41.7%)
	More than 1 week but less than 1 month	4 (33.3%)
	More than 1 month but less than 2 months	1 (8.3%)
	There is not wait, diagnosis is given when screened	2 (16.7%)
	Total Valid Response	12 (100.0%)
	Total missing	1

Type of Treatment	Question	Response/time	Ophthalmologist
Laser photocoagulation	Is the treatment available?	Available within country	5 (41.7%)
		Available locally	5 (41.7%)
		Available in practice	11 (91.7%)
		Total valid response	12 (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)	9 (81.8%)
		Mean	2.4
		SD	2.2
		Median	2.0

Type of Treatment	Question	Response/time	Ophthalmologist
		Min	1
		Max	8
		Don't know/not sure	1 (9.1%)
		Not applicable	1 (9.1%)
		Total valid response	11 (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)	10 (90.9%)
		Mean	1.6
		SD	1.1
		Median	1.0
		Min	0
		Max	3
		Don't know/not sure	1 (9.1%)
		Total valid response	11 (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)	10 (90.9%)
		Mean	1.9
		SD	1.4
		Median	2.0
		Min	0
		Max	4
		Don't know/not sure	1 (9.1%)
		Total valid response	11 (100.0%)
		Total missing	2
Anti-VEGF therapies	Is the treatment available?	Available within country	4 (33.3%)



Type of Treatment	Question	Response/time	Ophthalmologist
		Available in practice	11 (91.7%)
		Total valid response	12 (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)	9 (90.0%)
		Mean	2.0
		SD	2.4
		Median	1.0
		Min	0
		Max	8
		Don't know/not sure	1 (10.0%)
		Total valid response	10 (100.0%)
		Total missing	3
	What is the average amount of time your patients wait for a first treatment?(weeks)	Total valid numeric response (n)	10 (90.9%)
		Mean	1.3
		SD	0.8
		Median	1.0
		Min	0
		Max	3
		Don't know/not sure	1 (9.1%)
		Total valid response	11 (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)	10 (90.9%)
		Mean	1.6
		SD	1.4
		Median	1.0

Type of Treatment	Question	Response/time	Ophthalmologist
		Min	0
		Max	4
		Don't know/not sure	1 (9.1%)
		Total valid response	11 (100.0%)
		Total missing	2
Intravitreal steroid	Is the treatment available?	Available within country	4 (33.3%)
		Available locally	5 (41.7%)
		Available in practice	10 (83.3%)
		Total valid response	12 (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 (50.0%)
		Mean	2.8
		SD	3.0
		Median	1.0
		Min	1
		Max	8
		Don't know/not sure	3 (30.0%)
		Not applicable	2 (20.0%)
		Total valid response	10 (100.0%)
		Total missing	3
	What is the average amount of time your patients wait for a first treatment?(weeks)	Total valid numeric response (n)	6 (54.5%)
	L	Mean	1.7
		SD	1.0
		Median	1.0
		Min	1
		Max	3



Type of Treatment	Question	Response/time	Ophthalmologist
		Don't know/not sure	4 (36.4%)
		Not applicable	1 (9.1%)
		Total valid response	11 (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)	5 (50.0%)
		Mean	1.8
		SD	1.6
		Median	1.0
		Min	0
		Max	4
		Don't know/not sure	4 (40.0%)
		Not applicable	1 (10.0%)
		Total valid response	10 (100.0%)
		Total missing	3
Uncomplicated vitrectomy	Is the treatment available?	Available within country	4 (33.3%)
		Available locally	5 (41.7%)
		Available in practice	4 (33.3%)
		Not available	1 (8.3%)
		Total valid response	12 (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)	6 (60.0%)
		Mean	2.7
		SD	2.1
		Median	2.0
		Min	1
		Max	6

Type of Treatment	Question	Response/time	Ophthalmologist
		Don't know/not sure	2 (20.0%)
		Not applicable	2 (20.0%)
		Total valid response	10 (100.0%)
		Total missing	3
	What is the average amount of time your patients wait for a first treatment?(weeks)	Total valid numeric response (n)	5 (55.6%)
		Mean	2.4
		SD	1.5
		Median	2.0
		Min	1
		Max	4
		Don't know/not sure	3 (33.3%)
		Not applicable	1 (11.1%)
		Total valid response	9 (100.0%)
		Total missing	4
	What is the average amount of time your patients wait for a second treatment?(weeks)	Total valid numeric response (n)	5 (50.0%)
		Mean	2.2
		SD	1.8
		Median	2.0
		Min	0
		Max	4
		Don't know/not sure	3 (30.0%)
		Not applicable	2 (20.0%)
		Total valid response	10 (100.0%)
		Total missing	3
Complex vitreo- retinal surgery	Is the treatment available?	Available within country	6 (50.0%)
		Available locally	4 (33.3%)



Type of Treatment	Question	Response/time	Ophthalmologist
	1	Available in practice	2 (16.7%)
		Not available	2 (16.7%)
		Total valid response	12 (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)	6 (66.7%)
		Mean	3.0
		SD	2.4
		Median	2.0
		Min	1
		Max	6
		Don't know/not sure	1 (11.1%)
		Not applicable	2 (22.2%)
		Total valid response	9 (100.0%)
		Total missing	4
	What is the average amount of time your patients wait for a first treatment?(weeks)	Total valid numeric response (n)	6 (66.7%)
		Mean	2.3
		SD	2.0
		Median	1.5
		Min	1
		Max	6
		Don't know/not sure	2 (22.2%)
		Not applicable	1 (11.1%)
		Total valid response	9 (100.0%)
		Total missing	4
	What is the average amount of time your patients wait for a second treatment?(weeks)	Total valid numeric response (n)	5 (55.6%)

Type of Treatment	Question	Response/time	Ophthalmologist
		Mean	12.0
		SD	22.5
		Median	1.0
		Min	0
		Max	52
		Don't know/not sure	2 (22.2%)
		Not applicable	2 (22.2%)
		Total valid response	9 (100.0%)
		Total missing	4

Question	Response	Ophthalmologist
Do you personally administer treatment for diabetic retinopathy?	Yes	10 (90.9%)
	No	1 (9.1%)
	Total valid response	11 (100.0%)
	Total missing	2
Who administer it?	Another provider in your practice	1 (100.0%)
	Total valid response	1 (100.0%)
	Total missing	12

Question	Response	Ophthalmologist
Do any of the following influence how you treat diabetic retinopathy or diabetic macular edema?	Diabetes duration	5 (50.0%)
	Patient's age	6 (60.0%)
	Patient's gender	2 (20.0%)
	Presence of comorbidities such as hypertension, etc.	7 (70.0%)
	High glucose levels	7 (70.0%)
	Patient educational level	2 (20.0%)
	Patient adherence to	5 (50.0%)



Question	Response	Ophthalmologist
	recommendations	
	None of the above	1 (10.0%)
	Not applicable	1 (10.0%)
	Total valid response	10 (100.0%)
	Total missing	3

Question	Response	Ophthalmologist
Do you treat diabetic retinopathy and diabetic macular edema based on:	Both	11 (100.0%)
	Total Valid Response	11 (100.0%)
	Total missing	2

# PT 4.9

Question	Response	Ophthalmologist
How are your patients with diabetes screened for diabetic eye disease?	Fundoscopy undilated	1 (9.1%)
	Fundoscopy dilated	9 (81.8%)
	Retinal photo	6 (54.5%)
	Optical Coherence Tomography	6 (54.5%)
	Fluorescein Angiography	1 (9.1%)
	Total valid response	11 (100.0%)
	Total missing	2

Question	Response	Ophthalmologist
In your opinion, do the majority of your patients present:	In time for screening	10 (90.9%)
	When visual problems have already occurred	1 (9.1%)
	Total Valid Response	11 (100.0%)
	Total missing	2

Question	Response	Ophthalmologist
Have you received training specifically on treatment and diagnosis of diabetic retinopathy and/or clinically significant diabetic macular edema?	Yes	7 (63.6%)
	No	4 (36.4%)
	Total valid response	11 (100.0%)
	Total missing	2
If yes, When was your last training?	Five or more years ago	2 (28.6%)
	Greater than 1 year ago but less than 5 years	4 (57.1%)
	Within the past year	1 (14.3%)
	Total valid response	7 (100.0%)
	Total missing	6

Question	Response	Ophthalmologist
Would you be interested in online education and certification on DME, Angiogenesis and Anti-VEGF therapies?	Yes	7 (63.6%)
	No	4 (36.4%)
	Total Valid Response	11 (100.0%)
	Total missing	2

# PT 4.13

Question	Response	Ophthalmologist
How is outreach for screening for diabetic eye disease done in your main practice?	Health fairs for all	1 (10.0%)
	Health fairs for people with diabetes	1 (10.0%)
	Mobile screening centers	2 (20.0%)
	At vision centers	4 (40.0%)
	Other	5 (50.0%)
	Total valid response	10 (100.0%)
	Total missing	3



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	2 (25.0%)
	Late diagnosis	1 (12.5%)
	Referral pathways	2 (25.0%)
	Limited access to patient education on diabetic retinopathy and diabetic macular edema	2 (25.0%)
	No universal guidelines on referral/screening	1 (12.5%)
	No universal guidelines on how to treat	1 (12.5%)
	No universal guideline on when to treat	1 (12.5%)
	Current available therapies not effective	1 (12.5%)
	Government/insurance not able to cover patient costs	2 (25.0%)
	Multi-disciplinary team integration is poor	1 (12.5%)
	Other	2 (25.0%)
	Total valid response	8 (100.0%)
	Total missing	5

Question	Response	Without DED (%)	With DED (%)	With DME (%)
Which of the following complications of diabetes do you have?	Cardiovascular disease/Stroke	8 (11.8%)	2 (40.0%)	1 (50.0%)
	Irritable bowel disease	4 (5.9%)	1 (20.0%)	1 (50.0%)
	Kidney disease	3 (4.4%)	1 (20.0%)	1 (50.0%)
	Loss of feeling in hands or toes (neuropathy)	17 (25.0%)	3 (60.0%)	1 (50.0%)
	Vision loss	3 (4.4%)	3 (60.0%)	1 (50.0%)
	Foot ulcers	2 (2.9%)	2 (40.0%)	0 (0.0%)
	Amputation	2 (2.9%)	0 (0.0%)	0 (0.0%)
	Broken bones or fractures	1 (1.5%)	0 (0.0%)	0 (0.0%)
	Other	1 (1.5%)	0 (0.0%)	0 (0.0%)

Question	Response	Without DED (%)	With DED (%)	With DME (%)
	None	37 (54.4%)	0 (0.0%)	0 (0.0%)
	Don't know/Not sure	5 (7.4%)	1 (20.0%)	0 (0.0%)
	Total Valid Response	68 (100.0%)	5 (100.0%)	2 (100.0%)
	Total missing	3	1	0

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

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

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

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

#### EXP 2

Limitations	Without DED n (%)	With DED n (%)	With DME n (%)
Limited in any way in any activities because of impairment or health problem	28 (41.2%)	4 (100.0%)	2 (100.0%)
Impairment or health problem			
Diabetes	28 (87.5%)	4 (100.0%)	1 (50.0%)
Walking problem	22 (73.3%)	3 (75.0%)	2 (100.0%)
Back or neck problem	22 (71.0%)	3 (75.0%)	1 (50.0%)
Hypertension/high blood pressure	15 (50.0%)	2 (50.0%)	1 (50.0%)
Lung/breathing problem	15 (48.4%)	2 (50.0%)	2 (100.0%)
Mental or emotional health	9 (33.3%)	4 (100.0%)	1 (50.0%)
Arthritis/rheumatism	9 (32.1%)	2 (50.0%)	1 (50.0%)
Eye/vision problem	6 (21.4%)	4 (100.0%)	2 (100.0%)
Fractures, bone/joint injury	5 (17.9%)	1 (25.0%)	1 (50.0%)
Hearing problem	5 (17.9%)	1 (25.0%)	1 (50.0%)
Heart problem	5 (17.2%)	1 (25.0%)	1 (50.0%)
Cancer	2 (6.9%)	0 (0.0%)	0 (0.0%)
Stroke problem	1 (3.6%)	0 (0.0%)	1 (50.0%)

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

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

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

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

Health Status	Without DED (%)	With DED (%)	With DME (%)
Self-rated health: Good	31 (47.0%)	2 (40.0%)	1 (50.0%)
Self-rated health: Poor	35 (53.0%)	3 (60.0%)	1 (50.0%)
Physically unhealthy days	25 (43.9%)	3 (75.0%)	1 (100.0%)

Health Status	Without DED (%)	With DED (%)	With DME (%)
Mentally unhealthy days	20 (32.3%)	2 (100.0%)	1 (100.0%)
Unhealthy days	33 (55.9%)	3 (100.0%)	1 (100.0%)
Activity limitation days	18 (50.0%)	2 (66.7%)	1 (100.0%)

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

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

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

#### EXP 4

Item	Response	All respondents	Respondents with Type I diabetes	Respondents with Type II diabetes
How do you manage your diabetes?	Diet	33 (42.9%)	5 (50.0%)	28 (43.8%)
	Oral medicine	49 (63.6%)	4 (40.0%)	44 (68.8%)
	Exercise	32 (41.6%)	5 (50.0%)	25 (39.1%)
	Insulin	33 (42.9%)	9 (90.0%)	22 (34.4%)
	Natural/Herbal medicine	3 (3.9%)	1 (10.0%)	2 (3.1%)
	None of the above	2 (2.6%)		2 (3.1%)

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	24 (35.3%)	2 (40.0%)	1 (50.0%)
	Working without pay at home (e.g. housework, farming)	2 (2.9%)	0 (0.0%)	0 (0.0%)
	Volunteering	1 (1.5%)	0 (0.0%)	0 (0.0%)
	Retired	21 (30.9%)	1 (20.0%)	0 (0.0%)
	Student	1 (1.5%)	0 (0.0%)	0 (0.0%)
	Not working	19 (27.9%)	2 (40.0%)	1 (50.0%)
	Total Valid Response	68 (100.0%)	5 (100.0%)	2 (100.0%)
	Total missing	3	1	0
Do you receive assistance from the government?	Income assistance	8 (11.8%)	0 (0.0%)	0 (0.0%)
	Medical assistance	2 (2.9%)	2 (40.0%)	1 (50.0%)

Item	Response	Without DED (%)	With DED (%)	With DME (%)
	Food assistance	2 (2.9%)	0 (0.0%)	0 (0.0%)
	Housing assistance	2 (2.9%)	0 (0.0%)	0 (0.0%)
	Pension assistance	3 (4.4%)	1 (20.0%)	0 (0.0%)
	None of the above	53 (77.9%)	3 (60.0%)	1 (50.0%)
	Total valid response	68 (100.0%)	5 (100.0%)	2 (100.0%)
	Total missing	3	1	0
Did you have trouble paying for food at anytime during the past year?	Yes	29 (43.3%)	2 (40.0%)	2 (100.0%)
	No	38 (56.7%)	3 (60.0%)	0 (0.0%)
	Total Valid Response	67 (100.0%)	5 (100.0%)	2 (100.0%)
	Total missing	4	1	0

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

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

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

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

Item	Response	Without DED (%)	With DED (%)	With DME (%)
Are you currently working?	Working for pay	2 (66.7%)	0 (0.0%)	1 (100.0%)
	Student	1 (33.3%)	0 (0.0%)	0 (0.0%)
	Total Valid Response	3 (100.0%)	0 (0.0%)	1 (100.0%)
	Total missing	2	0	0
Do you receive assistance from the government?	Medical assistance	1 (33.3%)	0 (0.0%)	1 (100.0%)
	None of the above	2 (66.7%)	0 (0.0%)	0 (0.0%)
	Total valid response	3 (100.0%)	0	1 (100.0%)
	Total missing	2	0	0
Did you have trouble paying for food at anytime during the past year?	Yes	1 (33.3%)	0 (0.0%)	1 (100.0%)
	No	2 (66.7%)	0 (0.0%)	0 (0.0%)



Item	Response	Without DED (%)	With DED (%)	With DME (%)
	Total Valid Response	3 (100.0%)	0 (0.0%)	1 (100.0%)
	Total missing	2	0	0

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

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

Item	Response	Without DED (%)	With DED (%)	With DME (%)
Are you currently working?	Working for pay	15 (46.9%)	1 (33.3%)	0 (0.0%)
	Working without pay at home (e.g. housework, farming)	1 (3.1%)	0 (0.0%)	0 (0.0%)
	Volunteering	1 (3.1%)	0 (0.0%)	0 (0.0%)
	Retired	1 (3.1%)	0 (0.0%)	0 (0.0%)
	Not working	14 (43.8%)	2 (66.7%)	1 (100.0%)
	Total Valid Response	32 (100.0%)	3 (100.0%)	1 (100.0%)
	Total missing	1	1	0
Do you receive assistance from the government?	Income assistance	8 (25.0%)	0 (0.0%)	0 (0.0%)
	Medical assistance	1 (3.1%)	1 (33.3%)	0 (0.0%)
	Food assistance	1 (3.1%)	0 (0.0%)	0 (0.0%)
	Housing assistance	2 (6.3%)	0 (0.0%)	0 (0.0%)
	None of the above	22 (68.8%)	2 (66.7%)	1 (100.0%)
	Total valid response	32 (100.0%)	3 (100.0%)	1 (100.0%)
	Total missing	1	1	0
Did you have trouble paying for food at anytime during the past year?	Yes	18 (56.3%)	1 (33.3%)	1 (100.0%)
	No	14 (43.8%)	2 (66.7%)	0 (0.0%)
	Total Valid Response	32 (100.0%)	3 (100.0%)	1 (100.0%)
	Total missing	1	1	0

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

NB [2]: DED = respondents with DED ="Yes" minus respondents with DME ="Yes". NB [3]: DME = respondents with DME ="Yes".

# EXP 5.4: Age group 60-79 years

Item	Response	Without DED (%)	With DED (%)	With DME (%)
Are you currently working?	Working for pay	7 (22.6%)	1 (50.0%)	0 (0.0%)
	Working without pay at home (e.g. housework, farming)	1 (3.2%)	0 (0.0%)	0 (0.0%)
	Retired	18 (58.1%)	1 (50.0%)	0 (0.0%)
	Not working	5 (16.1%)	0 (0.0%)	0 (0.0%)
	Total Valid Response	31 (100.0%)	2 (100.0%)	0 (0.0%)
Do you receive assistance from the government?	Medical assistance	0 (0.0%)	1 (50.0%)	0 (0.0%)
	Food assistance	1 (3.2%)	0 (0.0%)	0 (0.0%)
	Pension assistance	3 (9.7%)	1 (50.0%)	0 (0.0%)
	None of the above	27 (87.1%)	1 (50.0%)	0 (0.0%)
	Total valid response	31 (100.0%)	2 (100.0%)	0
	Total missing	0	0	0
Did you have trouble paying for food at anytime during the past year?	Yes	10 (33.3%)	1 (50.0%)	0 (0.0%)
	No	20 (66.7%)	1 (50.0%)	0 (0.0%)
	Total Valid Response	30 (100.0%)	2 (100.0%)	0 (0.0%)
	Total missing	1	0	0

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

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

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

Item	Response	Without DED (%)	With DED (%)	With DME (%)
Are you currently working?	Retired	2 (100.0%)	0 (0.0%)	0 (0.0%)
	Total Valid Response	2 (100.0%)	0 (0.0%)	0 (0.0%)
Do you receive assistance from the government?	None of the above	2 (100.0%)	0 (0.0%)	0 (0.0%)



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

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

Group	Subgroup	All	Type 1	Type 2	With	With
		respondents	diabetes	diabetes	DED (%)	DME (%)
All respondents		79 (100%)	11 (13.9%)	65 (82.3%)	6 (7.6%)	2 (2.5%)
Gender	Male	44 (59.5%)	5 (11.4%)	38 (86.4%)	2 (4.5%)	1 (2.3%)
	Female	30 (40.5%)	4 (13.3%)	25 (83.3%)	3 (10.0%)	1 (3.3%)
	Total Missing	5	2	2	1	0
Age	18-39 yrs	6 (7.6%)	3 (50.0%)	2 (33.3%)	0 (0.0%)	1 (16.7%)
	40-59 yrs	38 (48.1%)	4 (10.5%)	33 (86.8%)	4 (10.5%)	1 (2.6%)
	60-79 yrs	33 (41.8%)	4 (12.1%)	28 (84.8%)	2 (6.1%)	0 (0.0%)
	80 yrs and over	2 (2.5%)	0 (0.0%)	2 (100.0%)	0 (0.0%)	0 (0.0%)
Time since diagnosis	Within the last year	5 (6.3%)	1 (20.0%)	3 (60.0%)	0 (0.0%)	0 (0.0%)
	1 - 5 years ago	30 (38.0%)	3 (10.0%)	26 (86.7%)	2 (6.7%)	2 (6.7%)
	6 - 10 years ago	19 (24.1%)	0 (0.0%)	19 (100.0%)	1 (5.3%)	0 (0.0%)
	11 - 15 years ago	13 (16.5%)	2 (15.4%)	11 (84.6%)	0 (0.0%)	0 (0.0%)
	16 - 20 years ago	4 (5.1%)	2 (50.0%)	2 (50.0%)	1 (25.0%)	0 (0.0%)
	21 years ago or longer	7 (8.9%)	3 (42.9%)	3 (42.9%)	2 (28.6%)	0 (0.0%)
	Don't know/Not sure	1 (1.3%)	0 (0.0%)	1 (100.0%)	0 (0.0%)	0 (0.0%)
Control of	Controlled	62 (82.7%)	8 (12.9%)	53 (85.5%)	4 (6.5%)	1 (1.6%)

Group	Subgroup	All respondents	Type 1 diabetes	Type 2 diabetes	With DED (%)	With DME (%)
Diabetes						
	Not controlled	11 (14.7%)	1 (9.1%)	10 (90.9%)	1 (9.1%)	1 (9.1%)
	Don't know/Not sure	2 (2.7%)	0 (0.0%)	1 (50.0%)	0 (0.0%)	0 (0.0%)
	Total Missing	4	2	1	1	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 (%)
Have you had any treatment for diabetic eye disease?	Yes	3 (50.0%)	2 (100.0%)
	No	3 (50.0%)	0 (0.0%)
	Total valid response	6 (100.0%)	2 (100.0%)
What treatment did you receive?	Laser	2 (66.7%)	1 (50.0%)
	Anti-VEGF	0 (0.0%)	1 (50.0%)
	Other	1 (33.3%)	0 (0.0%)
	Total valid response	3 (100.0%)	2 (100.0%)
	Total missing	3	0
Did you complete the treatment?	Yes	2 (66.7%)	1 (50.0%)
	No	0 (0.0%)	1 (50.0%)
	Still receiving treatment	1 (33.3%)	0 (0.0%)
	Total valid response	3 (100.0%)	2 (100.0%)
	Total missing	3	0
Do you feel that the treatment worked?	Yes, and vision improved	0 (0.0%)	1 (100.0%)
	Yes, but vision stayed the same	2 (66.7%)	0 (0.0%)
	Still waiting to know	1 (33.3%)	0 (0.0%)
	Total valid response	3 (100.0%)	1 (100.0%)
	Total missing	3	1
What is/are the reason(s) that you did not complete the treatment?	I was fearful (scared) of treatment	0 (0.0%)	1 (100.0%)
	Total valid response	0 (0.0%)	1 (100.0%)



Question	Response	With DED n (%)	With DME n (%)
	Total missing	6	1
What are the reason(s) that you have not had treatment for diabetic eye disease?	My doctor did not recommend any treatment	1 (50.0%)	0 (0.0%)
	Treatment would not be effective	1 (50.0%)	0 (0.0%)
	Treatment is not accessible	1 (50.0%)	0 (0.0%)
	Total valid response	2 (100.0%)	0 (0.0%)
	Total missing	4	2

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

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

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



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