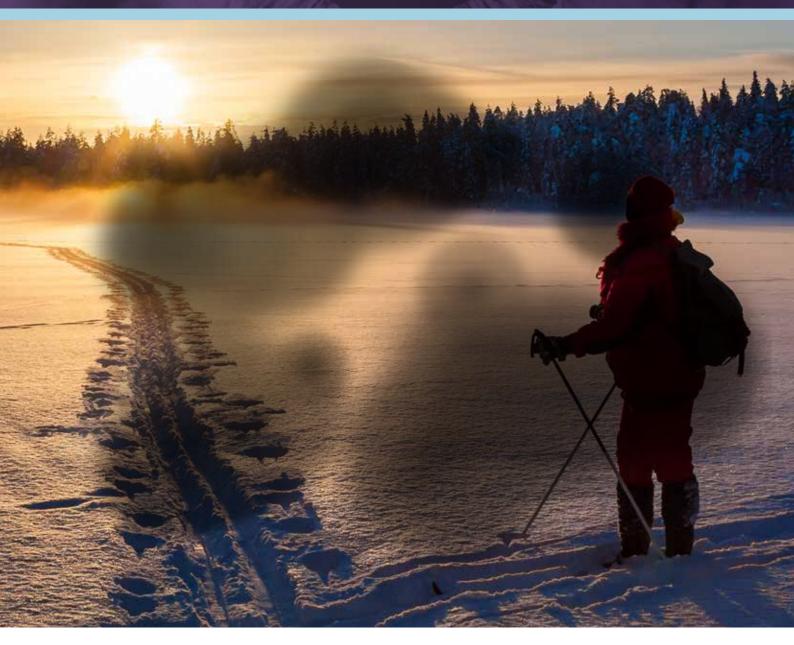


## The Diabetic Retinopathy Barometer Report













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For detailed information regarding methodology and limitations of the study please refer to the DR Barometer Global Results Report which can be found at **DRBarometer.com** 



## Introduction Global Study

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

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

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

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

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

## Goal

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

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

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

## Background

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

Phase II was a multi-country quantitative study conducted in 41 countries to investigate the current level of awareness of the risk of DR and of the need for prevention, screening and management to prevent vision loss. The study also sought to better understand the nature of health services and supports available and the social and economic burden of the disease through a systematic literature review. In the quantitative component of the study, both adults with diabetes (patients) and health care professionals (providers) were surveyed. The patient survey consisted of 46 questions divided into four sections covering awareness and knowledge, current care for diabetes and eye complications, screening and treatment of DR and DME, and quality of life.

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

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

#### **Study Populations**

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

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

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

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

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

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



# Introduction Finland Study

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

Finland is estimated to be the eighteenth most populous country in the European Union and twentysixth in Europe with a population of approximately 5.4 million. According to recent statistics, it is estimated that ~16% of the population is under the age of 15 years and ~21% over the age of 65 years.

Similarly, to many Nordic countries, Finland's population is expected to slowly and steadily increase during the next few decades despite its current ageing population, high life expectancy, and low fertilities rates. By 2050, it is projected that Finland's population will be 5.7million with those under the age of 15 years continuing to make ~15% of the total population and those aged 65 years and older will make up ~27% of the total population. In just over thirty years' time, Finland's population group aged 65 or older will see an increase of 31%, increasing from 1.1 million to 1.5 million.

## **Diabetes in Finland**<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. Finland has over 360,000 (270.4-442.4‡) adults living with diabetes, which accounts to ~0.6% of people living with diabetes in this region. The diabetes national prevalence in Finland (20 – 79 years) is 9% (6.7-11.0‡) and the age-adjusted comparative prevalence is 6% (4.3-7.8‡). Finland has the highest incidence in the world for the number of new cases of type 1 diabetes for people under 15 years of age at an estimated 62.3 cases per 100,000 population per year.

Deaths attributed to diabetes in Finland in 2015 were 2,878, which accounts to ~0.4% of the diabetes related deaths experienced in this region. The estimated number of undiagnosed cases was 138,900 [140.1-229.3‡].

## **Study Populations: Finland**

As reported by 86 respondents with diabetes in Finland, 37% were diagnosed with DED and a further 17% with DME.

Eight health care professionals completed the survey in Finland. Of these, four were ophthalmologists (50%), two were primary care providers (25%), and there were no diabetes specialist providers. The remaining respondents were either nurses or health educators.

## The DR Barometer Study: Finland Overview

The DR Barometer study was conducted in 41 countries. In Finland, 86 adults with diabetes and 8 health care professionals provided new information about the experiences of living with, managing and treating diabetes, DR and DME.

# 34%

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



# 25%

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

**DR:** Diabetic Retinopathy **DME:** Diabetic Macular Edema

DRBarometer.com







37%

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



# 65%

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

# 100%

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

13%

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

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

## Key Demographic Characteristics

Eighty-six adults with diabetes completed the patients' survey in Finland: 76% were female and 24% were male. Eighty-five percent lived in an urban setting and 15% in a non-urban setting (see Appendix Table 4.2).

The education levels of respondents was: 1.4% did not complete primary school, 16% were educated to a primary school level, 21% to a secondary school level, 21% to a college or university level, and 40% to a graduate or post-graduate level (see Appendix Table 4.3).

Fifty-one percent of respondents were in paid employment, 23% were retired and 12% were not working (see Appendix Table 4.4). Most of those surveyed (41%) were aged between 18 and 39 years (37% were 40-59 years and 22% were 60-79 years). Seventyeight percent were of traditional working age (18- 59 years) (see Table 1).

Of the respondents in Finland, 92% had been diagnosed with type 1 diabetes and 7% with type 2 diabetes. A further 1.2% of respondents were either unsure of or did not know their type of diabetes (see Appendix Table 2.1).

Thirty-seven percent of respondents (n=32) had been diagnosed with DED and a further 17% (n=15) with DME.

Two percent of those surveyed were diagnosed with diabetes within the last year, 1 - 5 years ago (3.5%), 6 - 10 years ago (7%), 11 - 15 years ago (12%), 16 - 20 years ago (9.3%), and 21 years ago or more (65%) (see Appendix Table 2.2).

All 18 to 39-year-olds had type 1 diabetes. In the 40-59 age group, 84% had type 1 (13% type 2) diabetes and in the 60-79-year-olds had 90% had type 1 diabetes (11% type 2).

In people aged 18-39 years, 43% had DED and 20% had DME. This increased to 44% for DED and 16% for DME in those aged 40-59 years and for people aged 60-79 years to 16% in both diseases.

In the first 5 years since diagnosis of diabetes, no one had DED and a third were diagnosed with DME. In those diagnosed between 11-15 years, 50% had DED and no respondents had DME; 40% diagnosed 21 years ago or longer had DED and 25% had DME.

While most (65%) respondents reported that their diabetes was well controlled, more than one in three felt that this was not that case. For those who felt their diabetes was controlled, 37% had DED and 17% had DME and for those not well controlled, 39% had DED and 21% had DME.

Group	Subgroup	All Respondents	Type 1 diabetes	Type 2 diabetes	With DED	With DME
All respondents		86 (100.0%)	79 (91.9%)	6 (7.0%)	32 (37.2%)	15 (17.4%)
Gender	Male	18 (24.0%)	15 (83.3%)	2 (11.1%)	4 (22.2%)	3 (16.7%)
	Female	57 (76.0%)	54 (94.7%)	3 (5.3%)	28 (49.1%)	12 (21.1%)
	Total Missing	11	10	1	0	0
Age	18-39 yrs.	35 (40.7%)	35 (100.0%)	0 (0.0%)	15 (42.9%)	7 (20.0%)
	40-59 yrs.	32 (37.2%)	27 (84.4%)	4 (12.5%)	14 (43.8%)	5 (15.6%)
	60-79 yrs.	19 (22.1%)	17 (89.5%)	2 (10.5%)	3 (15.8%)	3 (15.8%)
Time since diagnosis	Within the last year	2 (2.3%)	1 (50.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	1 - 5 yrs.	3 (3.5%)	1 (33.3%)	2 (66.7%)	0 (0.0%)	1 (33.3%)
	6 - 10 yrs.	6 (7.0%)	6 (100.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	11 - 15 yrs.	10 (11.6%)	9 (90.0%)	1 (10.0%)	5 (50.0%)	0 (0.0%)
	16 - 20 yrs.	8 (9.3%)	7 (87.5%)	1 (12.5%)	3 (37.5%)	0 (0.0%)
	21 yrs. plus	56 (65.1%)	54 (96.4%)	2 (3.6%)	24 (42.9%)	14 (25.0%)
	Don't know or Not sure	1 (1.2%)	1 (100.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Control of Diabetes	Controlled	54 (65.1%)	48 (88.9%)	5 (9.3%)	20 (37.0%)	9 (16.7%)
	Not controlled	28 (33.7%)	27 (96.4%)	1 (3.6%)	11 (39.3%)	6 (21.4%)
	Don't know or Not sure	1 (1.2%)	1 (100.0%)	0 (0.0%)	1 (100.0%)	0 (0.0%)
	Total Missing	3	3	0	0	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

Most (99%) respondents saw a health care professional for their diabetes, with 82% seeing a diabetes specialist (on average 2.3 times per year) and 8.3% seeing a general or family doctor (on average 3 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-four percent received information from a doctor or nurse, 74% from the internet and 69% from a diabetes organisation or other health organisation (see Table 2 and Appendix Table 2.4).

# Table 2: Source of information about diabetes

Information Source	All Respondents (n=84)
Doctor or nurse	79 (94.0%)
Internet	62 (73.8%)
Diabetes organisation or other health organisation	58 (69.0%)
Nutritionist or dietician	39 (46.4%)
Social media (e.g. Facebook, Twitter, blogs)	35 (41.7%)
TV or Radio or Newspaper or Magazines	25 (29.8%)
Family or Friends or Neighbours	21 (25.0%)
Health educator	18 (21.4%)
Pharmacist	1 (1.2%)
None of the above	1 (1.2%)

A range of strategies was used by respondents to manage their diabetes. For those with type 1 diabetes, apart from insulin, 61% managed their diabetes with diet, 51% with exercise and 16% with oral medicine. Of the respondents with type 2 diabetes, all managed with diet, 80% with oral medicine, 80% with exercise, 60% with insulin and 20% with natural or herbal medicine.

Only 8% of respondents were enrolled in diabetes management programmes and of these, 83% 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 had included blood glucose checks and eye checks. For those who had eye checks (90%), these occurred at less than 6 months (46%), 6 - 12 months (24%) and greater than 12 months (20%) (see Appendix Table 2.7).

The main challenges in controlling diabetes cited by respondents were: it was too hard to eat the right things (26%), there were too many other things to do (24%), the long wait times for an appointment to see their doctor or specialist (13%), the high cost of care (7.3%), and not having insurance (7.3%) (see Appendix Table 2.9).

Free or low cost medicines or monitoring materials (80%), support groups (43%), support from family or friends (41%), coordination of healthcare and services by a professional (27%), and health education and information (21%) were identified as important to improving the management of their diabetes (see Appendix Table 2.10).



# Nature and Information about Complications

Ninety-one percent of respondents were aware of neuropathy and believed other complications, such as: vision loss (89%), amputation (85%), foot ulcers (84%), and kidney disease (83%) were associated with diabetes (see Appendix Table 2.11).

Patients were most concerned about vision loss (46%), kidney disease (16%), cardiovascular disease or stroke (14%), neuropathy (5%), and amputation (2.5%) (see Appendix Table 2.12).

Thirty-eight percent of respondents had no complications of diabetes. However, of those with complications: 23% had neuropathy, kidney disease (13%), vision loss (11%), cardiovascular disease or stroke (8.9%), and amputation (3.8%) (see Figure 1 and Appendix Table 2.13).

Over two-thirds of people with DED (72%) and 93% of those with DME had complications associated with their condition (see Table 3 and EXP 1). Aside from vision loss, there was an increase in the frequency of people with DED and DME experiencing complications compared to those without DED. For example, 13% without DED had neuropathy compared with 28% with DED and 33% with DME and 3.1% without DED had kidney disease, versus 16% with DED and to 27% with DME representing a five-fold increase.

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

#### Figure 1: Presence of complications

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

Complication	Without DED (n=32)	With DED (n=32)	With DME (n=15)
Any	12 (37.5%)	23 (71.9%)	14 (93.3%)
Loss of feeling in hands or toes (neuropathy)	4 (12.5%)	9 (28.1%)	5 (33.3%)
Kidney disease	1 (3.1%)	5 (15.6%)	4 (26.7%)
Cardiovascular disease or Stroke	1 (3.1%)	4 (12.5%)	2 (13.3%)
Vision loss	2 (6.3%)	3 (9.4%)	4 (26.7%)
Foot ulcers	0 (0.0%)	1 (3.1%)	2 (13.3%)
Amputation	1 (3.1%)	0 (0.0%)	2 (13.3%)
Other	3 (9.4%)	10 (31.3%)	4 (26.7%)
None	20 (62.5%)	9 (28.1%)	1 (6.7%)

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

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

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

 $\mathsf{NB}\left[4\right]:\mathsf{Percentages}$  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-two percent of respondents said that eye complications were discussed with their health care professionals. Notwithstanding this general finding, the timing of the discussion about eye complication was varied, with some 37% who had, either never discussed their eye complications (17%), or the discussion only took place once symptoms arose (20%). The frequency of regular discussions varied from every visit (18%), multiple times a year (7.6%) and once a year (37%) (see Appendix Table 2.14).

Most (90%) respondents said that they did what they could to prevent vision problems (e.g. get routine screenings, visit specialists) yet 15% thought that vision problems were a normal part of ageing and 6% made no special effort to have a preventative approach to their eye health (see Appendix Table 2.15).

Eighty-four percent of respondents had received information about DR and DME with the doctor or nurse being the most common source (65%) (see Table 4 and Appendix Table 3.9).

# Table 4: Source of information about DR and DME

Source	All respondents (n=74)
Doctor or Nurse	48 (64.9%)
Internet	35 (47.3%)
Diabetes organisation or other health organisation	26 (35.1%)
TV or Radio or Newspaper or Magazines	4 (5.4%)
Family or Friends or Neighbours	2 (2.7%)
Health educator	1 (1.4%)
None of the above	12 (16.2%)

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

All respondents had an eye exam for DED, with 78% having it within the last year and a further 16% more than one year ago but less than two years ago. Fifty-six percent were aware of government sponsored screening programmes for DED (see Appendix Table 3.1 and 3.2).

While 68% of those surveyed thought they should have their eyes examined for DED once a year, 28% said it should only happen every two years and one person said that testing should happen less than every two years (see Appendix Table 3.4).

The biggest barriers to eye exams were long wait times for an appointment (34%), the referral was long and complicated (22%), and the exams were very costly (17%) (see Table 5 and Appendix Table 3.5).

#### Table 5: Barriers to eye examinations

Identified Barriers	All Respondents (n=41)
Long wait time for appointment	14 (34.1%)
Referral process is complicated or takes too long	9 (22.0%)
They are expensive	7 (17.1%)
Long wait time on the day of the visit	5 (12.2%)
Fear of treatment or results	5 (12.2%)
Limited access to diabetes specialists	4 (9.8%)
Recommended treatments for eye problems are not available	3 (7.3%)
Eye exams are not available near my home	2 [4.9%]
Don't know much about my condition	2 (4.9%)
I'm not likely to have eye complications	2 [4.9%]
Burden on my family or friends	1 (2.4%)
Other	7 (17.1%)

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

Treatment was assessed separately in people with DED and in those with DME.

For those with DED (53%) all received laser treatment which was ongoing for almost one-third (29%) of the respondents. Over two-thirds had completed treatment and 83% of those felt that treatment had been successful and their vision had either improved (18%) or had stayed the same (65%) (see Table 6).

For the fourteen respondents (44%) with DED and four with DME who had not received treatment, the most common reason was that their doctor did not recommend treatment.

Seventy-one percent of respondents with DME (n=10) received laser treatment and most felt that treatment had been successful with their vision either improving (40%) or staying the same (50%).

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

Question	Response	With DED (n=32)	With DME (n=15)
Have you had any treatment for diabetic eye disease?	Yes	17 (53.1%)	10 (71.4%)
	No	14 (43.8%)	4 (28.6%)
	Don't know or Not sure	1 (3.1%)	0 (0.0%)
What treatment did you receive?	Laser	16 (100.0%)	10 (100.0%)
	Anti-VEGF	3 (18.8%)	3 (30.0%)
	Surgery	1 (6.3%)	5 (50.0%)
Did you complete the treatment?	Yes	11 (64.7%)	8 (80.0%)
	Still receiving treatment	5 (29.4%)	2 (20.0%)
	Don't know or Not sure	1 (5.9%)	0 (0.0%)
Do you feel that the treatment worked?	Yes, and vision improved	3 (17.6%)	4 (40.0%)
	Yes, but vision stayed the same	11 (64.7%)	5 (50.0%)
	Still waiting to know	2 (11.8%)	1 (10.0%)
	Don't know or Not sure	1 (5.9%)	0 (0.0%)
What are the reason(s) that you have not had treatment for diabetic eye disease?	My doctor did not recommend any treatment	9 (69.2%)	3 (75.0%)
	Treatment is not accessible	1 (7.7%)	0 (0.0%)
	Treatment is not important to me	1 (7.7%)	0 (0.0%)
	Other	5 (38.5%)	1 (25.0%)

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

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

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

NB [3]: Not all respondents answered all questions in the survey; percentages are calculated from non-missing responses to the survey question. NB [4]: This table is a summary of various questions. For a detailed breakdown for each question, please refer to the Appendices.



## Impact of Diabetic Eye Disease and Diabetic Macular Edema

Over half of those diagnosed with DED or DME said that their vision was affected (11% significantly, 41% slightly) (see Appendix Table 3.6).

Nearly two-thirds (65%) reported that vision issues impacted their daily lives in various ways such as difficulty driving a vehicle (44%), leisure activities or exercise (26%), working or keeping a job (22%), managing their underlying diabetes (13%), travelling (8.7%), undertaking household responsibilities, such as cooking or cleaning (8.7%) and social interactions with family or friends (8.7%) (see Table 7).

# Table 7: Treatment characteristics ofpatients with DED and DME

	All Respondents (n=23)
Driving (a car or vehicle)	10 (43.5%)
Leisure activities or exercise	6 (26.1%)
Work or keeping a job	5 (21.7%)
Managing my diabetes	3 (13.0%)
Travelling	2 (8.7%)
Household responsibilities, such as cooking or cleaning	2 (8.7%)
Social interactions with family or friends	2 (8.7%)
Other	4 (17.4%)
None	8 (34.8%)

Despite changes in vision, 56% of those with DED and 43% with DME were in paid employment compared with 48% of respondents without DED (see Table 8 and EXP 5.1). Patients with vision complications did however report difficulties with work or keeping a job (22%) and 13% of those with DED (n=4) were not working at all.

Most (80%) respondents did not receive assistance from the government while 11% received medical assistance. Most (80%) had no trouble paying for food at any time during the past year and 80% didn't feel access to healthcare was affected however for 14% it was affected by the place where they lived (see Appendix Table 4.5, 4.6 and 4.7).

Sixty-five percent of respondents worried about their health, 2.8% about family while 14% were not worried about any of the items in the survey (see Appendix Table 4.8).

Question	Response	Without DED (n=27)	With DED (n=32)	With DME (n=14)
Are you currently working?	Working for pay	13 (48.1%)	18 (56.3%)	6 (42.9%)
	Working without pay at home (e.g. housework, farming)	1 (3.7%)	2 [6.3%]	1 (7.1%)
	Retired	5 (18.5%)	7 (21.9%)	5 (35.7%)
	Student	4 (14.8%)	1 (3.1%)	1 (7.1%)
	Not working	4 (14.8%)	4 (12.5%)	1 (7.1%)
Question	Response	Without DED (n=26)	With DED (n=28)	With DME (n=11)
Do you receive assistance from the government?	Income assistance	3 (11.5%)	1 (3.6%)	1 (9.1%)
	Medical assistance	3 (11.5%)	2 (7.1%)	2 (18.2%)
	Food assistance	1 (3.8%)	2 (7.1%)	1 (9.1%)
	Housing assistance	2 (7.7%)	2 (7.1%)	2 (18.2%)
	Pension assistance	0 (0.0%)	1 (3.6%)	0 (0.0%)
	None of the above	20 (76.9%)	24 (85.7%)	8 (72.7%)
Question	Response	Without DED (n=27)	With DED (n=32)	With DME (n=14)
Did you have trouble paying for food at any time during the past year?	Yes	5 (18.5%)	5 (15.6%)	5 (35.7%)
	Νο	22 (81.5%)	27 (84.4%)	9 (64.3%)

#### Table 8: Socio-economic profile 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.



## Self-reported Quality of Life

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

Sixty-three percent of people with DED, 50% of those with DME and 37% without DED said that their health was poor. Proportionally more respondents with DED and DME experienced unhealthy days, both physical and mental compared to those without DED. Furthermore, those with eye complications were more likely to have days where their activity level was limited (48% DED, 50% DME, and 41% without DED).

People living with DED and DME had a higher proportion for some impairments. Of note were potential mobility challenges manifested through back or neck problems, eye or vision problems, mental or emotional problems and arthritis or rheumatism.

		· · · · · · · · · · · · · · · · · · ·	
Health Status	Without DED	With DED	With DME
Self-rated health: Good	17 (63.0%)	11 (36.7%)	7 (50.0%)
Self-rated health: Poor	10 (37.0%)	19 (63.3%)	7 (50.0%)
Physically unhealthy days	13 (61.9%)	21 (77.8%)	9 (81.8%)
Mentally unhealthy days	13 (56.5%)	14 (51.9%)	8 (66.7%)
Unhealthy days	17 (77.3%)	21 (80.8%)	12 (100.0%)
Activity limitation days	7 (41.2%)	11 (47.8%)	6 (50.0%)

#### 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.

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

## **Key Demographic Characteristics**

There were eight health care professionals who answered at least one of the survey questions in Finland. Of these, two were primary care providers (25%), and four were ophthalmologists (50%). The remaining respondents were nurses and health educators (see Appendix PT 1.3). It is important to note that the sample size was notable small and should be taken into consideration.

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

Health care professionals as a group had been practicing for an average of 11 years, with the ophthalmologist group practicing for an average of 7.3 years (see Appendix PT 1.5). All providers were well educated (100% with graduate or advanced degree); 67% were female and 33% male; and 67% were aged 40 - 49 years with a further 33% in the 30-39 age groups (see Appendix PT 3.1 and Table 10).

Group	Subgroup	All Respondents	Primary Care Provider	Diabetes Specialist	Ophthalmologist
All respondents		8 (100.0%)	2 (25.0%)	4 (50.0%)	10 (13.3%)
Age group	30 - 39 yrs.	1 (33.3%)	0 (0.0%)	1 (33.3%)	1 (14.3%)
	40 - 49 yrs.	2 (66.7%)	0 (0.0%)	2 (66.7%)	1 (14.3%)
Gender	Female	2 (66.7%)	0 (0.0%)	2 (66.7%)	2 (28.6%)
	Male	1 (33.3%)	0 (0.0%)	1 (33.3%)	3 (42.9%)
Education	Graduate or advanced degree (e.g. PhD, MD, etc.)	3 (100.0%)	0 (0.0%)	3 (100.0%)	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

Forty percent of the providers had their main practice in a diabetes clinic or practice and for ophthalmologists only the settings were eye clinic (33%), hospital (33%), and other sites (33%) (see Appendix PT 2.1). All health care professionals surveyed worked in an urban setting (see Appendix PT 2.2).

Most health care professionals worked in the government sector (60%) and ophthalmologists worked in the government (67%) and private (33%) sectors (see Appendix PT 2.3).

Most (80%) patients don't pay for services, 40% pay through insurance, and 20% pay a reduced or subsidised rate for services and the pattern was similar for ophthalmologists, where 67% of patients do not pay for services, and 33% pay a reduced or subsidised rate for services or pay out-of-pocket (full fees) for services (see Appendix PT 2.7). On average providers see 36 patients per week with 53% (on average) having diabetes while ophthalmologists see 42 patients per week with some 22% having diabetes (see Appendix PT 2.6).

The average waiting time (all providers) for an appointment was most commonly more than one month but less than two months (40%), or less than one week (20%) (see Appendix PT 2.5).

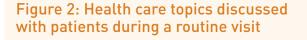
Timing for an appointment with an ophthalmologist was similar, 67% between one and two months, 33% more than one week but less than one month.

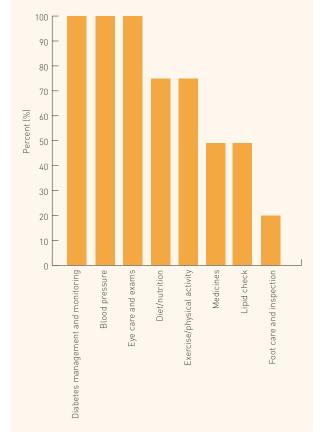
# Table 11: Average wait times to schedule an appointment

Wait Time Intervals	All Respondents (n=5)	Ophthalmologist (n=3)
Less than 1 week	1 (20.0%)	0 (0.0%)
More than 1 week but less than 1 month	1 (20.0%)	1 (33.3%)
More than 1 month but less than 2 months	2 (40.0%)	2 (66.7%)
Other	1 (20.0%)	0 (0.0%)

## **Patient Education Information**

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





Health care professionals stated that written information about diabetes is available yet the adequacy of that related to eye complications varies. Half the providers had sufficient information about eye complications, while the remainder said that it was insufficient (see Table 12 and Appendix PT 2.11).

A third of ophthalmologists (had written information about diabetes and potential eye complications but of concern is the finding that 67% reported that information on eye complications was not sufficient.



## **Guidelines and Protocols**

Fifty percent of providers and 33% of ophthalmologists had written protocols for the management of diabetes, which were used by staff, yet one quarter had no protocols (see Appendix PT 2.12).

With respect to the management of diabetes-related vision issues, all health care professionals and ophthalmologists had written protocols, which were used by staff (see Table 12 and Appendix PT 2.13).

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

Question	Response	All Respondents (n=4)	Ophthalmologist (n=3)
Is there written information about diabetes available	Yes, and information on eye complications is sufficient	2 (50.0%)	1 (33.3%)
for patients in your main practice?	Yes, but information on eye complications is not sufficient	2 (50.0%)	2 (66.7%)
Question	Response	All Respondents (n=3)	Ophthalmologist (n=2)
Do you have written protocols or guidelines for detection and management of diabetes-related vision issue available in your main practice?	Yes, available and used by staff	3 (100.0%)	2 (100.0%)

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

## Screening Protocols and Barriers in the Care Pathway

Timing for the initial eye exam for persons with diabetes did not vary depending upon the type of diabetes. For those with either type 1 or type 2 diabetes all providers said that the initial eye exam should occur at time of the diagnosis of diabetes (see Appendix PT 2.14).

Overall, twenty-five percent of health care professionals and 33% of ophthalmologists believe that follow-up eye examinations should be conducted every year. Half of ophthalmologists and one third of health care professionals screen patients for DR (see Appendix PT 2.15 and PT 2.16)

Across all health care professionals, 67% send appointment reminders. About twothirds (67%) of the health care professionals and ophthalmologists shared information to optimise patient care management (see Appendix PT 2.19 and PT 2.20). The most common patient characteristics influencing the referral process for eye complications for health care professionals were: presence of comorbidities such as hypertension (100%), high glucose levels (100%), diabetes duration (67%), the patient's age (33%), and the patient's ability to adhere to recommendations (33%) (see Appendix PT 2.17).

As reported by ophthalmologists, the major barriers to optimising eye health faced by patients with diabetes were that the patients feel eye exams were not important (67%), long wait times for an appointment (33%) and long wait times on the day of visit (33%). Notably the sample size is very small (see Appendix PT 2.18).



## Table 13: Major barriers to optimising eye health

Response	Ophthalmologists (n=3)
Patients feel eye exams are not important	2 (66.7%)
Long wait time for appointment	1 (33.3%)
Long wait time on the day of visit	1 (33.3%)
Referral process	1 (33.3%)
Lack of knowledge and or awareness	1 (33.3%)
Patients fear of treatment or results	1 (33.3%)
Patients feel they are a burden on family or friends	1 (33.3%)
Patients feel eye complications are unlikely	1 (33.3%)

# **Finland DR Barometer Findings:** Ophthalmologists

## Screening

There were three ophthalmologists who answered at least one of the supplementary questions (see Appendix PT 4.1 to PT 4.14). On average 13% of patients seen by the ophthalmologists had DR and 11% DME (see Appendix PT 4.1 and PT 4.2). It is important to note that the sample size was notable small and should be taken into consideration.

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

## **Treatment and Challenges**

Seventy-five percent of ophthalmologists personally administer treatment for DR (see Appendix PT 4.6) and the most factors influencing treatment were: the duration of diabetes (67%), the presence of comorbidities such as hypertension (67%) and high glucose levels (67%) (see Appendix PT 4.7). The most common outreach venues for screening for DED were health fairs for people with diabetes (50%) and mobile screening centres (50%) (see Appendix PT 4.13).

All ophthalmologists reported that their patients with diabetes are screened for DR based on retinal photos and 33% on fundoscopy through dilated pupils: 67% treat DR and DME based on both visual and anatomical outcomes (see Appendix PT 4.8 and PT 4.9).

Three-quarters of the ophthalmologists received specific training on treatment and diagnosis of DR and or DME: 67% in the past year and 33% more than one year ago but less than five years (see Appendix PT 4.11). Most (75%) were interested in online education and certification on DME, angiogenesis and anti-VEGF therapies (see Appendix PT 4.12).

Ophthalmologists perceived the challenges for improving patient outcomes in DED included complex and inadequate care pathways, no universal guidelines, the nature of current treatments (see Table 14 and PT 4.14).



## Table 14: Challenges for improving outcomes in DED

Question	Response	Ophthalmologists (n=3)
What do you perceive to be the	Referral pathways	1 (33.3%)
greatest challenges for improving patient outcomes in diabetic eye	No universal guidelines on how to treat	1 (33.3%)
disease?	Current available therapies not effective	1 (33.3%)
	Other	1 (33.3%)

# Finland DR Barometer Summary

In Finland, 86 adults with diabetes and eight health care professionals have provided insight about their experiences of living with, managing and treating diabetes, DR and DME.

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

Similar to many Nordic countries, Finland's population is expected to slowly and steadily increase during the next few decades despite its currently large ageing population, high life expectancy, and low fertilities rates. According to most recent statistics, 16% of the population is under the age of 15 years and ~21% over the age of 65 years.

By 2050 it is expected that Finland's population will be 5.7million with those under the age of 15years continuing to make ~15% of the total population and those aged 65 years and older will make up ~27% of the total population. In just over thirty years' time, Finland's population group aged 65 years or older will see an increase of 31%, increasing from 1.1 million to 1.5 million.

Alongside the demographic changes, Finland has over 360,000 (270.4-442.4‡) adults living with diabetes with a national prevalence 20 – 79 years of 9% (6.7-11.0‡). Deaths attributed to diabetes in Finland in 2015 were 2,878, and the estimated number of undiagnosed cases was 138,900 (140.1-229.3‡). Finland has the highest incidence globally for the number of new cases of type 1 diabetes for people under 15 years of age at an estimated 62.3 cases per 100,000 population per year.

In the study all 18 to 39 year-olds had type 1 diabetes. In the 40-59 age group, 84% had type 1 (13% type 2 diabetes) and in the 60-79 year-olds 90% had type 1 diabetes (11% type 2).

People were most often informed about their condition by health professionals such as the doctor, nurse, and nutritionist. A trend globally, which was reflected in the Finland study, was the increasing use of the internet by almost three-quarters (74%) of the respondents. To a lesser extent diabetes and other health organisations, the nutritionist and the social media played were also viewed as valuable sources of information.

Only 8% of respondents were enrolled in diabetes management programmes and most (83%) noted there was education on the importance of screening for eye complications.

Many of those surveyed struggled with the management of their diabetic condition with some issues that were within their personal control such as eating the right foods and balancing the responsibilities of family and work without compromising their only health. In addition, long wait times for appointments, the high cost of care and no insurance were challenges.



There was a relatively high awareness of the complications associated with diabetes. Vision loss (46%) was by far the most concerning followed by kidney disease and cardiovascular disease. Only 38% of those surveyed had no complications – neuropathy, kidney disease and vision loss were the top three complications experienced by respondents.

While the number of respondents was small, most of those with DED and DME had complications and there was a general increase in the frequency compared to those without DED. For example neuropathy (DED 28%, DME 33% vs without DED 13%), kidney disease (DED 16%, DME 27% vs without DED 3.1%).

Knowing that diabetic-related vision loss is preventable addressing barriers to eye screening is an important policy issue. While all respondents had received an eye exam, which is understandable considering the purposeful sample, there remained many barriers including long wait times for an appointment, the referral was long and complicated, and the exams were very costly.

Evidence shows that the relationship between the patient and the health care professional is critical to ensure realistic and optimal patient outcomes. It was therefore surprising that 37% of patients surveyed had either never had a conversation about eye complications with their health professional or it only took place only when symptoms were present. Equally concerning is the myths and perceptions around vision changes with more that 15% of patients reporting that vision problems were a normal part of ageing and some not making any special effort to prevent vision problems.

Over half of those with DED or DME said that their vision was slightly or significantly affected which in turn impacted their health, lifestyle, and life choices. The diagnosis of DED and DME generally indicated a greater likelihood of poor health, as well as physically and mentally unhealthy days compared with those without DED. For example poor health 63% DED, 50% DME and 37% without DED and reported physically unhealthy days 78% DED, 82% DME and 62% without DED.

Nearly two-thirds of those with DED and DME experienced difficulty in driving a vehicle, leisure activities including exercise, working or keeping a job, and undertaking household responsibilities, managing their diabetes.

A proactive treatment approach to prevent further vision loss was preferred rather than reactive treatment once further vision loss had occurred. However, for some (14%) respondents access to healthcare was affected by where they actually lived. Patient education is very much at the heart of a proactive approach so it was somewhat unexpected to find that over 50% of providers said that the written information diabetes and eye complications available was not sufficient. All providers reported to have written protocols for the detection and management of diabetes-related vision issues that were used by staff.

For both patients with either type 1 or type 2 diabetes all providers said that an initial eye exam should occur at time of the diagnosis of diabetes. In regards to followup eye examinations 25% of health care professionals and 33% of ophthalmologists reported that follow-up eye examinations should be annual.

The top three patient characteristics influencing the referral process for eye complications across providers, high glucose levels, and duration of diabetes.

Complex and inadequate care pathways, no universal guidelines, and the nature of current treatments were viewed by ophthalmologists as some of the greatest challenges for improving patient outcomes in DED. In large part, the patients and providers who participated in the study were selfselected, and therefore this population group is more likely to be engaged and motivated in the management of their diabetes hence a possible explanation for the rates of awareness and screening.

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



# **References and Acknowledgement**

- <sup>1</sup> The World Bank. (2016). *Health nutrition and population statistics: Population estimates and projections* (World Data Bank). Washington, D.C.: The World Bank. Retrieved from http://databank.worldbank. org/data/reports.aspx?source=Health %20Nutrition%20and%20Population%20 Statistics:%20Population%20estimates %20and%20projections
- <sup>2</sup> International Diabetes Federation. (2015). *IDF Diabetes Atlas*. Accessed from: http://www.diabetesatlas.org/

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# **Appendices**

30 The Diabetic Retinopathy Barometer Report: Finland



# The Diabetic Retinopathy Barometer Survey: Appendices for Finland

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

#### Table 1.1

Survey Information	Number of Respondents (%)
All valid respondents [1]	91 (100.0%)
Respondents aged 18 or over	90 (98.9%)
Respondents with diabetes	87 (95.6%)

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

#### Table 1.2

Survey Information	Number of Respondents (%)
All valid respondents	91 (100.0%)
Included in Diabetic Analysis Set	86 (94.5%)
Excluded from Diabetic Analysis Set	5 (5.5%)
Reasons for exclusion from diabetic analysis set	•
Under 18 years of age	1
Not diagnosed with diabetes	2
Missing information on diabetes diagnosis	1
Gestational diabetes only	1

#### Table 1.3

Survey Information	Number of Respondents (%)
Diabetic Analysis Set	86 (100.0%)
World Bank Income Group: High Income	86 (100.0%)
Persons with diabetic eye disease (DED)	32 (37.2%)
Persons with diabetic macular edema (DME)	15 (17.4%)
Persons with Type I diabetes	79 (91.9%)
Persons with Type II diabetes	6 (7.0%)
Persons not seeing health care professional for diabetes	1 (1.2%)
Persons seeing health care professional for diabetes	85 (98.8%)
Persons with eye disease & not received treatment	18 (20.9%)

Survey Information	Number of Respondents (%)
Persons with eye disease & received treatment	27 (31.4%)

#### Table 2.1

Question	Response	Number of Respondents (%)
With which type of diabetes have you been diagnosed?	Туре I	79 (91.9)
	Type II	6 (7.0)
	Don't know/Not sure	1 (1.2)
	Total Valid Response	86 (100.0)

#### Table 2.2

Question	Response	Number of Respondents (%)
When was your diabetes diagnosed?	Within the last year	2 (2.3)
	1 - 5 years ago	3 (3.5)
	6 - 10 years ago	6 (7.0)
	11 - 15 years ago	10 (11.6)
	16 - 20 years ago	8 (9.3)
	21 years ago or longer	56 (65.1)
	Don't know/Not sure	1 (1.2)
	Total Valid Response	86 (100.0)

#### Table 2.3.1

Question	Response	Number of Respondents (%)
Do you see a health care professional for your diabetes?	Yes	85 (98.8)
	No	1 (1.2)
	Total Valid Response	86 (100.0)
What kind of health care professional?	General/Family Doctor	7 (8.3)
	Nurse	6 (7.1)
	Diabetes Specialist	69 (82.1)
	Other	1 (1.2)



Question	Response	Number of Respondents (%)
	Don't know/Not sure of kind	1 (1.2)
	Total Valid Response	84 (100.0)
	Total missing	2

#### Table 2.3.2

Type of health care professional	Times per year seen for diabetes	Value
General/Family Doctor	Total valid numeric response (n)	5
	Mean	3.0
	SD	1.2
	Median	3.0
	Min	2
	Max	5
	Total missing	2
Nurse	Total valid numeric response (n)	4
	Mean	3.3
	SD	1.0
	Median	3.5
	Min	2
	Max	4
	Don't know/Not sure	1
	Total missing	1
Diabetes Specialist	Total valid numeric response (n)	58
	Mean	2.3
	SD	1.3
	Median	2.0
	Min	1
	Max	6
	Don't know/Not sure	2
	Total missing	9
Other	Total valid numeric response (n)	1
	Mean	2.0
	SD	

Type of health care professional	Times per year seen for diabetes	Value
	Median	2.0
	Min	2
	Max	2
Don't know/Not sure of kind	Don't know/Not sure	1

#### Table 2.4

Question	Response	Number of Respondents (%)
How have you received information about diabetes?	Doctor or nurse	79 (94.0%)
	Health educator	18 (21.4%)
	Nutritionist or dietitian	39 (46.4%)
	Diabetes organization or other health organization	58 (69.0%)
	Family/Friends/Neighbors	21 (25.0%)
	TV/Radio/Newspaper/Magazines	25 (29.8%)
	Internet	62 (73.8%)
	Social media (e.g. Facebook, Twitter, blogs)	35 (41.7%)
	Pharmacist	1 (1.2%)
	None of the above	1 (1.2%)
	Total Valid Response	84 (100.0%)
	Total missing	2

#### Table 2.5

Question	Response	Number of Respondents (%)
How do you manage your diabetes?	Diet	52 (63.4%)
	Oral medicine	16 (19.5%)
	Exercise	43 (52.4%)
	Insulin	79 (96.3%)
	Natural/Herbal medicine	3 (3.7%)
	Total Valid Response	82 (100.0%)
	Total missing	4



#### Table 2.6

Question	Response	Number of Respondents (%)
Are you currently enrolled in a diabetes patient management support programme?	Yes	7 (8.3)
	No	77 (91.7)
	Total Valid Response	84 (100.0)
	Total missing	2
Who sponsors the programme?	Hospital support program	2 (33.3)
	Patient organization support program	2 (33.3)
	Don't know/Not sure	2 (33.3)
	Total Valid Response	6 (100.0)
	Total missing	80
Does the programme include education on the importance of screening for diabetic eye complications?	Yes	5 (83.3)
	No	1 (16.7)
	Total Valid Response	6 (100.0)
	Total missing	80

#### Table 2.7

Test	Response	Number of Respondents (%)
Have you ever had the following tests in a doctors office of clinic? And if yes, how long ago?		
Blood glucose test	Yes	79 (96.3%)
	Less than 6 months	63 (76.8%)
	6 - 12 months	10 (12.2%)
	Greater than 12 months	6 (7.3%)
	Total valid response	79 (96.3%)
	Total missing	7
	No	3 (3.7%)

Test	Response	Number of Respondents (%)
	Total valid response	82 (100.0%)
	Total missing	4
Urine check	Yes	75 (93.8%)
	Less than 6 months	38 (47.5%)
	6 - 12 months	26 (32.5%)
	Greater than 12 months	10 (12.5%)
	Total valid response	74 (92.5%)
	Total missing	12
	No	5 (6.3%)
	Total valid response	80 (100.0%)
	Total missing	6
Weight check	Yes	82 (100.0%)
	Less than 6 months	54 (65.9%)
	6 - 12 months	16 (19.5%)
	Greater than 12 months	11 (13.4%)
	Total valid response	81 (98.8%)
	Total missing	5
	Total valid response	82 (100.0%)
	Total missing	4
Blood pressure check	Yes	83 (100.0%)
	Less than 6 months	63 (75.9%)
	6 - 12 months	17 (20.5%)
	Greater than 12 months	3 (3.6%)
	Total valid response	83 (100.0%)
	Total missing	3



Test	Response	Number of Respondents (%)
	Total valid response	83 (100.0%)
	Total missing	3
Foot check	Yes	76 (93.8%)
	Less than 6 months	37 (45.7%)
	6 - 12 months	26 (32.1%)
	Greater than 12 months	13 (16.0%)
	Total valid response	76 (93.8%)
	Total missing	10
	No	5 (6.2%)
	Total valid response	81 (100.0%)
	Total missing	5
Eye check	Yes	71 (89.9%)
	Less than 6 months	36 (45.6%)
	6 - 12 months	19 (24.1%)
	Greater than 12 months	16 (20.3%)
	Total valid response	71 (89.9%)
	Total missing	15
	No	7 (8.9%)
	Don't know/Not sure	1 (1.3%)
	Total valid response	79 (100.0%)
	Total missing	7

Question	Response	Number of Respondents (%)
How well do you think your diabetes is controlled?	Very well	13 (15.7%)

Question	Response	Number of Respondents (%)
	Well	41 (49.4%)
	Not very well	25 (30.1%)
	Not well at all	3 (3.6%)
	Don't know/Not sure	1 (1.2%)
	Total Valid Response	83 (100.0%)
	Total missing	3

Question	Response	Number of Respondents (%)
What are the main challenges you face in controlling your diabetes?	High cost of care	6 (7.3%)
	No insurance	6 (7.3%)
	Travel to my regular doctor or specialist is difficult	1 (1.2%)
	Long wait time for an appointment to see my doctor or specialist	11 (13.4%)
	Health services needed are not available	6 (7.3%)
	Don't know enough about diabetes	3 (3.7%)
	Too hard to eat the right things	21 (25.6%)
	Too many other things to do	20 (24.4%)
	Stigma or discrimination because of diabetes	4 (4.9%)
	Don't want to think about having diabetes	6 (7.3%)
	Other	29 (35.4%)
	Total Valid Response	82 (100.0%)
	Total missing	4

Question	Response	Number of Respondents (%)
Which of the following services currently	Free or low cost medicines or	65 (80.2%)



Question	Response	Number of Respondents (%)
help you better manage your diabetes?	monitoring materials	
	Support groups	35 (43.2%)
	Support from family or friends	33 (40.7%)
	Health education and information	17 (21.0%)
	Mobile services (services that travel to or near your home)	7 (8.6%)
	Coordination of healthcare and services by a professional	22 (27.2%)
	Emergency helpline	3 (3.7%)
	Other	11 (13.6%)
	None	2 (2.5%)
	Total Valid Response	81 (100.0%)
	Total missing	5

Question	Response	Number of Respondents (%)
What complications (or problems), to your knowledge, arise from diabetes?	Amputation	69 (85.2%)
	Foot ulcers	68 (84.0%)
	Increased risk of broken bones or fractures	18 (22.2%)
	Loss of feeling in hands or toes (neuropathy)	74 (91.4%)
	Vision loss	72 (88.9%)
	Irritable bowel disease	28 (34.6%)
	Kidney disease	67 (82.7%)
	Cardiovascular disease/Stroke	60 (74.1%)
	Other	19 (23.5%)
	Don't know/Not sure	1 (1.2%)
	Total Valid Response	81 (100.0%)
	Total missing	5

Question	Response	Number of Respondents (%)
Which complication of diabetes are you most concerned about?	Amputation	2 (2.5)
	Increased risk of broken bones or fractures	1 (1.3)
	Loss of feeling in hands or toes (neuropathy)	4 (5.0)
	Vision loss	37 (46.3)
	Irritable bowel disease	1 (1.3)
	Kidney disease	13 (16.3)
	Cardiovascular disease/Stroke	11 (13.8)
	Don't know/Not sure	3 (3.8)
	None	8 (10.0)
	Total Valid Response	80 (100.0)
	Total missing	6

Question	Response	Number of Respondents (%)
Which of the following complications of diabetes do you have?	Amputation	3 (3.8%)
	Foot ulcers	3 (3.8%)
	Broken bones or fractures	5 (6.3%)
	Loss of feeling in hands or toes (neuropathy)	18 (22.8%)
	Vision loss	9 (11.4%)
	Irritable bowel disease	8 (10.1%)
	Kidney disease	10 (12.7%)
	Cardiovascular disease/Stroke	7 (8.9%)
	Other	17 (21.5%)
	Don't know/Not sure	5 (6.3%)
	None	30 (38.0%)
	Total Valid Response	79 (100.0%)
	Total missing	7



Question	Response	Number of Respondents (%)
How often do you discuss the possibility of eye complications with your health care professional?	Every visit	14 (17.7%)
	Multiple times per year	6 (7.6%)
	Once per year	29 (36.7%)
	Only when symptoms arise	16 (20.3%)
	Never	13 (16.5%)
	Don't know/Not sure	1 (1.3%)
	Total Valid Response	79 (100.0%)
	Total missing	7

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	12 (15.0%)
	I do what I can to prevent vision problems (e.g. get routine screenings, visit specialists)	72 (90.0%)
	I do not make any special effort to prevent vision problems	5 (6.3%)
	Total Valid Response	80 (100.0%)
	Total missing	6

Question	Response	Number of Respondents (%)
What type of health insurance do you have?	Public	57 (71.3)
	Public - Private	7 (8.8)
	Private	3 (3.8)
	None	13 (16.3)
	Total Valid Response	80 (100.0)
	Total missing	6

Table 2	.17
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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	21 (29.6)
	Insurance and out-of- pocket/cash (e.g. co-pays)	25 (35.2)
	Out-of-pocket only (pay cash for all care)	17 (23.9)
	Do not use service	4 (5.6)
	Don't know/Not Sure	4 (5.6)
	Total Valid Response	71 (100.0)
	Total missing	15
Specialist medical visits (e.g. eye doctor, gynecologist, urologist)	Care is free	9 (12.7)
	Insurance and out-of- pocket/cash (e.g. co-pays)	24 (33.8)
	Out-of-pocket only (pay cash for all care)	36 (50.7)
	Do not use service	1 (1.4)
	Don't know/Not Sure	1 (1.4)
	Total Valid Response	71 (100.0)
	Total missing	15
Medicines	Care is free	22 (31.9)
	Insurance pays total cost	1 (1.4)
	Insurance and out-of- pocket/cash (e.g. co-pays)	33 (47.8)
	Out-of-pocket only (pay cash for all care)	12 (17.4)
	Don't know/Not Sure	1 (1.4)
	Total Valid Response	69 (100.0)
	Total missing	17
Medical supplies (e.g. blood glucose meter/strips)	Care is free	71 (95.9)
	Insurance and out-of- pocket/cash (e.g. co-pays)	1 (1.4)
	Do not use service	1 (1.4)



Question	Response	Number of Respondents (%)
	Don't know/Not Sure	1 (1.4)
	Total Valid Response	74 (100.0)
	Total missing	12
Procedures	Care is free	18 (26.5)
	Insurance and out-of- pocket/cash (e.g. co-pays)	21 (30.9)
	Out-of-pocket only (pay cash for all care)	12 (17.6)
	Do not use service	6 (8.8)
	Don't know/Not Sure	11 (16.2)
	Total Valid Response	68 (100.0)
	Total missing	18
Tests/screenings	Care is free	44 (63.8)
	Insurance and out-of- pocket/cash (e.g. co-pays)	6 (8.7)
	Out-of-pocket only (pay cash for all care)	5 (7.2)
	Do not use service	8 (11.6)
	Don't know/Not Sure	6 (8.7)
	Total Valid Response	69 (100.0)
	Total missing	17
Health education	Care is free	25 (37.9)
	Insurance pays total cost	1 (1.5)
	Insurance and out-of- pocket/cash (e.g. co-pays)	1 (1.5)
	Do not use service	34 (51.5)
	Don't know/Not Sure	5 (7.6)
	Total Valid Response	66 (100.0)
	Total missing	20
Counseling	Care is free	33 (50.8)
	Insurance and out-of- pocket/cash (e.g. co-pays)	3 (4.6)
	Do not use service	22 (33.8)
	Don't know/Not Sure	7 (10.8)
	Total Valid Response	65 (100.0)

Question	Response	Number of Respondents (%)
	Total missing	21

Question	Response	Number of Respondents (%)
Are you aware of any government sponsored screening programs for diabetic eye disease (diabetic retinopathy)?	Yes	43 (55.8%)
	No	34 (44.2%)
	Total valid response	77 (100.0%)
	Total missing	9

### Table 3.2

Question	Response	Number of Respondents (%)
Have you ever had an eye exam for diabetic eye disease?	Yes	78 (100.0%)
	Total valid response	78 (100.0%)
	Total missing	8
How long ago was your last eye exam?	Within the last year	59 (77.6%)
	More than 1 year ago but less than 2 years	12 (15.8%)
	More than 2 years ago but less than 3 years	4 (5.3%)
	More than 3 years ago but less than 5 years	1 (1.3%)
	Total valid response	76 (100.0%)
	Total missing	10
Who did the last exam?	General/Family practitioner	2 (2.6%)
	Eye doctor/Eye clinic	59 (77.6%)
	Other	14 (18.4%)
	Don't know/Not sure	1 (1.3%)
	Total valid response	76 (100.0%)
	Total missing	10



Question	Response	Number of Respondents (%)
Have you ever had a dilated eye exam, where your eyes are examined after eye drops?	Yes	73 (97.3%)
	No	2 (2.7%)
	Total valid response	75 (100.0%)
	Total missing	11

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	52 (68.4%)
	Every two years	21 (27.6%)
	Less often than every two years	1 (1.3%)
	Don't know/Not sure	2 (2.6%)
	Total valid response	76 (100.0%)
	Total missing	10

Question	Response	Number of Respondents (%)
For you, what are the biggest barriers to eye exams?	They are expensive	7 (17.1%)
	Eye exams are not available near my home	2 (4.9%)
	Long wait time for appointment	14 (34.1%)
	Long wait time on the day of the visit	5 (12.2%)
	Referral process is complicated or takes too long	9 (22.0%)
	Recommended treatments for eye problems are not available	3 (7.3%)
	Don't know much about my condition	2 (4.9%)
	Fear of treatment/results	5 (12.2%)
	Burden on my family/friends	1 (2.4%)

Question	Response	Number of Respondents (%)
	Limited access to diabetes specialists	4 (9.8%)
	I'm not likely to have eye complications	2 (4.9%)
	Other	7 (17.1%)
	Total valid response	41 (100.0%)
	Total missing	45

Question	Response	Number of Respondents (%)
Have you been diagnosed with diabetic eye disease?	Yes	46 (60.5%)
	No	30 (39.5%)
	Total valid response	76 (100.0%)
	Total missing	10
Has your diabetic eye disease affected your vision?	Yes, slightly	19 (41.3%)
	Yes, significantly	5 (10.9%)
	No	22 (47.8%)
	Total valid response	46 (100.0%)
	Total missing	40
Have vision issues caused you to have difficulty with any of the following?	Traveling	2 (8.7%)
	Household responsibilities, such as cooking or cleaning	2 (8.7%)
	Social interactions with family/friends	2 (8.7%)
	Leisure activities/exercise	6 (26.1%)
	Work or keeping a job	5 (21.7%)
	Managing my diabetes	3 (13.0%)
	Other	4 (17.4%)
	None	8 (34.8%)
	Driving (a car/vehicle)	10 (43.5%)
	Total valid response	23 (100.0%)
	Total missing	63



Question	Response	Number of Respondents (%)
Have you had any treatment for diabetic eye disease?	Yes	27 (58.7%)
	No	18 (39.1%)
	Don't know/Not sure	1 (2.2%)
	Total valid response	46 (100.0%)
	Total missing	40
What treatment did you receive?	Laser	26 (100.0%)
	Injection in the eye (Anti- VEGF)	6 (23.1%)
	Surgery	6 (23.1%)
	Total valid response	26 (100.0%)
	Total missing	60
Did you complete the treatment?	Yes	19 (70.4%)
	Still receiving treatment	7 (25.9%)
	Don't know/Not sure	1 (3.7%)
	Total valid response	27 (100.0%)
	Total missing	59
Do you feel that the treatment worked?	Yes, and vision improved	7 (25.9%)
	Yes, but vision stayed the same	16 (59.3%)
	Still waiting to know	3 (11.1%)
	Don't know/Not sure	1 (3.7%)
	Total valid response	27 (100.0%)
	Total missing	59
What is/are the reason(s) that you did not complete the treatment?	Total missing	86
What are the reason(s) that you have not had treatment for diabetic eye disease?	My doctor did not recommend any treatment	12 (70.6%)
	Treatment is not accessible	1 (5.9%)
	Treatment is not important to me	1 (5.9%)
	Other	6 (35.3%)
	Total valid response	17 (100.0%)
	Total missing	69

Question	Response	Number of Respondents (%)
Have you been diagnosed with diabetic macular edema?	Yes	15 (20.0%)
	No	53 (70.7%)
	Don't know/Not sure	7 (9.3%)
	Total valid response	75 (100.0%)
	Total missing	11
If Yes, which of the following would you prefer	Treatment to prevent further vision loss	14 (93.3%)
	Don't know/Not sure	1 (6.7%)
	Total valid response	15 (100.0%)
	Total missing	71

# Table 3.9

Question	Response	Number of Respondents (%)
Have you received information about diabetic retinopathy or diabetic macular edema from any of the following sources?	Doctor/Nurse	48 (64.9%)
	Health educator	1 (1.4%)
	Diabetes organization or other health organization	26 (35.1%)
	Family/Friends/Neighbors	2 (2.7%)
	TV/Radio/Newspaper/Magazines	4 (5.4%)
	Internet	35 (47.3%)
	None of the above	12 (16.2%)
	Total valid response	74 (100.0%)
	Total missing	12

# Table 4.1

Question	Response	Number of Respondents (%)
What is your gender?	Female	57 (76.0)
	Male	18 (24.0)



Question	Response	Number of Respondents (%)
	Total Valid Response	75 (100.0)
	Total missing	11
Please indicate your age	18 - 29	13 (15.1)
	30 - 39	22 (25.6)
	40 - 49	18 (20.9)
	50 - 59	14 (16.3)
	60 - 69	15 (17.4)
	70 - 79	4 (4.7)
	Total Valid Response	86 (100.0)

# Table 4.2

Question	Response	Number of Respondents (%)
Where do you live?	Urban setting	64 (85.3)
	Non-urban setting	11 (14.7)
	Total Valid Response	75 (100.0)
	Total missing	11

# Table 4.3

Question	Response	Number of Respondents (%)
What is the highest level of education you completed?	Did not complete primary school	1 (1.4)
	Primary school	11 (15.7)
	Secondary school	15 (21.4)
	College/University	15 (21.4)
	Graduate or post-graduate	28 (40.0)
	Total valid response	70 (100.0)
	Total missing	16

### Table 4.4

Question	Response	Number of Respondents (%)
Are you currently working?	Working for pay	37 (50.7)
	Working without pay at home (e.g.	4 (5.5)

Question	Response	Number of Respondents (%)
	housework, farming)	
	Retired	17 (23.3)
	Student	6 (8.2)
	Not working	9 (12.3)
	Total Valid Response	73 (100.0)
	Total missing	13

### Table 4.5

Question	Response	Number of Respondents (%)
Do you receive assistance from the government?	Income assistance	5 (7.7%)
	Medical assistance	7 (10.8%)
	Food assistance	4 (6.2%)
	Housing assistance	6 (9.2%)
	Pension assistance	1 (1.5%)
	None of the above	52 (80.0%)
	Total valid response	65 (100.0%)
	Total missing	21

# Table 4.6

Question	Response	Number of Respondents (%)
Did you have trouble paying for food at anytime during the past year?	Yes	15 (20.5)
	No	58 (79.5)
	Total Valid Response	73 (100.0)
	Total missing	13

# Table 4.7

Question	Response	Number of Respondents (%)
Do you feel that your access to health care is negatively	Age	4 (6.1)



Question	Response	Number of Respondents (%)
affected by any of the following?		
	Education	1 (1.5)
	Income	2 (3.0)
	Language you speak	1 (1.5)
	Place of birth	1 (1.5)
	Place where you live	9 (13.6)
	Race	1 (1.5)
	None of the above	53 (80.3)
	Total valid response	66 (100.0)
	Total missing	20

#### Table 4.8

Question	Response	Number of Respondents (%)
Which of the following do you worry about most?	Money	13 (18.1)
	Health	47 (65.3)
	Family	2 (2.8)
	None of the above	10 (13.9)
	Total Valid Response	72 (100.0)
	Total missing	14

#### Table 5.1

Question	Response	Number of Respondents (%)
In general, would you say your health is:	Excellent	4 (5.6%)
	Very good	9 (12.7%)
	Good	22 (31.0%)
	Total good health	35 (49.3%)
	Fair	29 (40.8%)
	Poor	7 (9.9%)

Question	Response	Number of Respondents (%)
	Fair or poor health	36 (50.7%)
	Total valid response	71 (100.0%)
	Total missing	15

### Table 5.2

Question	Response	Number of Respondents (%)
How many days during last 30 days was your physical health not good	Any unhealthy days	43 (72.9%)
	1-5 unhealthy days	17 (28.8%)
	6-10 unhealthy days	5 (8.5%)
	11-20 unhealthy days	10 (16.9%)
	21-30 unhealthy days	11 (18.6%)
	No unhealthy days	16 (27.1%)
	Total valid response	59 (100.0%)
	Total missing	27

### 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	35 (56.5%)
	1-5 unhealthy days	16 (25.8%)
	11-20 unhealthy days	5 (8.1%)
	21-30 unhealthy days	14 (22.6%)
	No unhealthy days	27 (43.5%)
	Total valid response	62 (100.0%)



Question	Response	Number of Respondents (%)
	Total missing	24

### Table 5.3.2

Question	Response	Number of Respondents (%)
Unhealthy days (physically or mentally unhealthy, max 30)	Any unhealthy days	50 (83.3%)
	1-5 unhealthy days	14 (23.3%)
	6-10 unhealthy days	5 (8.3%)
	11-20 unhealthy days	9 (15.0%)
	21-30 unhealthy days	22 (36.7%)
	No unhealthy days	10 (16.7%)
	Total valid response	60 (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	24 (46.2%)
	1-5 unhealthy days	14 (26.9%)
	6-10 unhealthy days	3 (5.8%)
	11-20 unhealthy days	4 (7.7%)
	21-30 unhealthy days	3 (5.8%)
	No unhealthy days	28 (53.8%)
	Total valid response	52 (100.0%)
	Total missing	34

### 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	44 (62.0%)
	No	27 (38.0%)
	Total valid response	71 (100.0%)
	Total missing	15
Which impairment or health problem, if any, limits your activities?		1
a) Arthritis/rheumatism	Yes	9 (25.0%)
	No	26 (72.2%)
	Don't know/Not sure	1 (2.8%)
	Total valid response	36 (100.0%)
	Total missing	50
b) Back or neck problem	Yes	21 (52.5%)
	No	17 (42.5%)
	Don't know/Not sure	2 (5.0%)
	Total valid response	40 (100.0%)
	Total missing	46
c) Fractures, bone/joint injury	Yes	12 (32.4%)
	No	25 (67.6%)
	Total valid response	37 (100.0%)
	Total missing	49
d) Walking problem	Yes	15 (38.5%)
	No	23 (59.0%)
	Don't know/Not sure	1 (2.6%)
	Total valid response	39 (100.0%)
	Total missing	47
e) Lung/breathing problem	Yes	4 (11.1%)



Question	Response	Number of Respondents (%)
	No	32 (88.9%)
	Total valid response	36 (100.0%)
	Total missing	50
f) Hearing problem	Yes	4 (11.1%)
	No	32 (88.9%)
	Total valid response	36 (100.0%)
	Total missing	50
g) Eye/vision problem	Yes	16 (40.0%)
	No	23 (57.5%)
	Don't know/Not sure	1 (2.5%)
	Total valid response	40 (100.0%)
	Total missing	46
h) Heart problem	Yes	4 (11.1%)
	No	31 (86.1%)
	Don't know/Not sure	1 (2.8%)
	Total valid response	36 (100.0%)
	Total missing	50
i) Stroke problem	Yes	2 (5.4%)
	No	34 (91.9%)
	Don't know/Not sure	1 (2.7%)
	Total valid response	37 (100.0%)
	Total missing	49
j) Hypertension/high blood pressure	Yes	11 (28.9%)
	No	26 (68.4%)
	Don't know/Not sure	1 (2.6%)
	Total valid response	38 (100.0%)

Question	Response	Number of Respondents (%)
	Total missing	48
k) Diabetes	Yes	31 (72.1%)
	No	10 (23.3%)
	Don't know/Not sure	2 (4.7%)
	Total valid response	43 (100.0%)
	Total missing	43
l) Cancer	Yes	1 (2.9%)
	No	34 (97.1%)
	Total valid response	35 (100.0%)
	Total missing	51
m) Mental or emotional health	Yes	15 (37.5%)
	No	23 (57.5%)
	Don't know/Not sure	2 (5.0%)
	Total valid response	40 (100.0%)
	Total missing	46

# PT 1.2

Analysis Sets	Number of Respondents (%)
All valid respondents	8 (100.0%)
Included in Provider Analysis Set (PAS)	8 (100.0%)
Excluded in Provider Analysis Set (PAS)	0 (0.0%)
Reasons for exclusion from Provider Analysis Set:	
No other valid survey data	0
Provider Analysis Set	8
Included in the Eye Care Professional Set (Eye Specialist)	4 (50.0%)
Excluded in the Eye Care Professional Set (Eye Specialist)	4 (50.0%)
Reasons for exclusion from Eye Care Professional Set:	
Missing required speciality	4



Analysis Sets	Number of Respondents (%)
No valid (non-missing) response for the supplemental eye questionnaire	0

### PT 1.3

Subgroups	Number of Respondents (%)
Provider Analysis Set	8 (100.0%)
Primary Care Provider	2 (25.0%)
Diabetes Specialist Provider	0 (0.0%)
Eye Care Professional	4 (50.0%)
Ophthalmologist	4 (50.0%)

NB [1]: Primary Care Provider = General Practitioner/Family practitioner (but not diabetes specialist or eye care professional) NB [2]: Diabetes specialist provider = Diabetes specialist (but not eye care professional)

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

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

#### PT 1.4

Item	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
What is your specialty?	General primary care/Family practitioner	2 (100.0%)	N/A	0 (0.0%)	2 (25.0%)
	Diabetes specialist	0 (0.0%)	N/A	1 (25.0%)	1 (12.5%)
	General ophthalmologist	0 (0.0%)	N/A	2 (50.0%)	2 (25.0%)
	Optometrist	0 (0.0%)	N/A	0 (0.0%)	0 (0.0%)
	Retinal specialist	0 (0.0%)	N/A	2 (50.0%)	2 (25.0%)
	Nurse	0 (0.0%)	N/A	0 (0.0%)	2 (25.0%)
	Health educator	1 (50.0%)	N/A	0 (0.0%)	1 (12.5%)
	None of the above	0 (0.0%)	N/A	0 (0.0%)	0 (0.0%)
	Total valid response	2 (100.0%)	0 (100.0%)	4 (100.0%)	8 (100.0%)
	Total missing	0	0	0	0

Item	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
How long have you been practicing in this profession?	Total valid response (n)	2		4	8
	Mean	0.0	•	7.3	11.4
	SD	0.0		6.6	13.3
	Median	0.0		7.0	7.0
	Min.	0		0	0
	Max.	0	•	15	32
	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%)	2 (40.0%)
	Eye clinic/practice	0 (0.0%)	0 (0.0%)	1 (33.3%)	1 (20.0%)
	General medical clinic/practice	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	Hospital	0 (0.0%)	0 (0.0%)	1 (33.3%)	1 (20.0%)
	Other	0 (0.0%)	0 (0.0%)	1 (33.3%)	1 (20.0%)
	Total Valid Response	0 (.%)	0 (0.0%)	3 (100.0%)	5 (100.0%)
	Total missing	2	0	1	3

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Where is your main practice located?	Urban setting	0 (0.0%)	0 (0.0%)	3 (100.0%)	5 (100.0%)
	Non-urban	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)



Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	setting				
	Total Valid Response	0 (.%)	0 (0.0%)	3 (100.0%)	5 (100.0%)
	Total missing	2	0	1	3

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
In which sector is your main practice?	Government	0 (0.0%)	0 (0.0%)	2 (66.7%)	3 (60.0%)
	Private	0 (0.0%)	0 (0.0%)	1 (33.3%)	1 (20.0%)
	Non profit	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	Combined/mixed	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (20.0%)
	Total Valid Response	0 (.%)	0 (0.0%)	3 (100.0%)	5 (100.0%)
	Total missing	2	0	1	3

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%)	3 (100.0%)	4 (80.0%)
	Yes, other	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (20.0%)
	Total valid response	0	0	3 (100.0%)	5 (100.0%)
	Total missing	2	0	1	3

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
What is the average wait time for an appointment in your main practice?	Less than 1 week	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (20.0%)
	More than 1 week but less than 1 month	0 (0.0%)	0 (0.0%)	1 (33.3%)	1 (20.0%)
	More than 1 month but less than 2 months	0 (0.0%)	0 (0.0%)	2 (66.7%)	2 (40.0%)
	Other	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (20.0%)
	Total Valid Response	0	0 (0.0%)	3 (100.0%)	5 (100.0%)
	Total missing	2	0	1	3

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
On average, how many patients do you see per week in your main practice [n patients]	Total valid response (n)	0	0	3	5
	Mean		N/A	41.7	36
	SD		N/A	7.6	12.9
	Median		N/A	40	40
	Min.		N/A	35	15
	Max.		N/A	50	50
	Total missing	2	0	1	3
What percentage of the patients in your main practice have diabetes [% patients]	Total valid response (n)	0	0	3	5
	Mean		N/A	22	53.2
	SD		N/A	13.9	43.8
	Median	•	N/A	30	30



Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Min.	•	N/A	6	6
	Max.		N/A	30	100
	Total missing	2	0	1	3

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
In your main practice, how do patients pay for the care and services that you provide?	Don't pay	0 (0.0%)	0 (0.0%)	2 (66.7%)	4 (80.0%)
	Pay a reduced/subsidized rate	0 (0.0%)	0 (0.0%)	1 (33.3%)	1 (20.0%)
	Pay out-of-pocket (full fees)	0 (0.0%)	0 (0.0%)	1 (33.3%)	1 (20.0%)
	Pay through insurance	0 (0.0%)	0 (0.0%)	1 (33.3%)	2 (40.0%)
	Other	0 (0.0%)	0 (0.0%)	1 (33.3%)	1 (20.0%)
	Total valid response	0	0	3 (100.0%)	5 (100.0%)
	Total missing	2	0	1	3

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
In addition to your main practice, do you work in another practice setting?	Yes			1 (25.0%)	1 (14.3%)
	No	1 (100.0%)		3 (75.0%)	6 (85.7%)
	Total valid response	1 (100.0%)		4 (100.0%)	7 (100.0%)

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

Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Blood glucose	Yes					2 (50.0%)
		_	0		0 (0.0%)	1 (25.0%)
		Mean		<u>.</u>		4.0
		SD				
		Median				4.0
		Min				4
		Max				4
		Total	2		4	7



Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	•	missing				
	No			_	2 (100.0%)	2 (50.0%)
	Total valid response				2 (100.0%)	4 (100.0%)
	Total missing		2		2	4
HbA1c	Yes			1		2 (50.0%)
		1	0		0 (0.0%)	1 (25.0%)
		Mean		J	L	4.0
		SD				1.0
		Median	-			4.0
		Min	-			4
		Max Total missing	2	]	4	4 7
	No			]	2 (100.0%)	2 (50.0%)
	Total valid response				2 (100.0%)	4 (100.0%)
	Total missing		2		2	4
Urine check		1	0	-	0 (0.0%)	0 (0.0%)
		Mean		1		
		SD	1			
		Median	1			
		Min	]			
		Max		_		
		Total missing	2		4	8
	No			-	2 (100.0%)	4 (100.0%)

Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Total valid				2 (100.0%)	4 (100.0%)
	response					(100.078)
	Total	-	2	]	2	4
	missing					
Weight check	Yes					2 (50.0%)
		-	0		0 (0.0%)	1 (25.0%)
		Mean		J		4.0
		SD	-			
		Median				4.0
		Min				4
		Max				4
		Total missing	2		4	7
	No		1	1	2 (100.0%)	2 (50.0%)
	Total valid				2 (100.0%)	4 (100.0%)
	response			_		
	Total missing		2		2	4
Blood pressure check	Yes			-		2 (50.0%)
		1	0		0 (0.0%)	1 (25.0%)
		Mean		J		4.0
		SD	-			
		Median	-			4.0
		Min				4
		Max	1			4
		Total missing	2		4	7
	No			1	2 (100.0%)	2 (50.0%)
	Total	-			2 (100.0%)	4



Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	valid response		·			(100.0%)
	Total missing		2		2	4
Foot check	Yes			-		2 (50.0%)
		1	0		0 (0.0%)	1 (25.0%)
		Mean				1.0
		SD				
		Median				1.0
		Min				1
		Max				1
		Total missing	2		4	7
	No			J	2 (100.0%)	2 (50.0%)
	Total valid response				2 (100.0%)	4 (100.0%)
	Total missing		2		2	4
Eye examination - Un-dilated		]	0		0 (0.0%)	0 (0.0%)
		Mean				
		SD	-			
		Median	-			
		Min	-			
		Max				
		Total missing	2		4	8
	No			_	2 (100.0%)	4 (100.0%)
	Total valid response				2 (100.0%)	4 (100.0%)

Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Total missing		2		2	4
Eye examination - Optical Coherence Tomography	Yes				2 (100.0%)	2 (50.0%)
	<u>.</u>	Total valid numeric response (n)	0		2 (100.0%)	2 (50.0%)
		Mean			3.0	3.0
		SD			0.0	0.0
		Median			3.0	3.0
		Min			3	3
		Max			3	3
		Total missing	2		2	6
	No			1		2 (50.0%)
	Total valid response				2 (100.0%)	4 (100.0%)
	Total missing	-	2		2	4
Eye examination - Fundoscopy	Yes	-	L	1	3 (100.0%)	3 (60.0%)
		Total valid numeric response (n)	0		3 (100.0%)	3 (60.0%)
		Mean		1	2.3	2.3
		SD	1		1.2	1.2
		Median	1		3.0	3.0
		Min	1		1	1
		Max	1		3	3
		Total missing	2		1	5
	No				<u></u>	2



Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
						(40.0%)
	Total valid response				3 (100.0%)	5 (100.0%)
	Total missing		2		1	3
Eye Ye examination - Fluorescein Angiography	Yes			1	1 (50.0%)	1 (25.0%)
		Total valid numeric response (n)	0		1 (50.0%)	1 (25.0%)
		Mean		1	1.0	1.0
		SD				1
		Median			1.0	1.0
		Min			1	1
		Max			1	1
		Total missing	2	]	3	7
	No		1	1	1 (50.0%)	3 (75.0%)
	Total valid response				2 (100.0%)	4 (100.0%)
	Total missing	-	2	]	2	4
Eye examination - Lipid check	Yes			_	1 (50.0%)	1 (25.0%)
		Total valid numeric response (n)	0		1 (50.0%)	1 (25.0%)
		Mean			2.0	2.0
		SD	-		L	1
		Median	-		2.0	2.0
		Min	-		2	2
		Max	1		2	2

Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
		Total missing	2		3	7
	No				1 (50.0%)	3 (75.0%)
	Total valid response				2 (100.0%)	4 (100.0%)
	Total missing		2		2	4

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
In your main practice, what topics do you cover during a routine visit with a patient who has diabetes?	Diabetes management and monitoring	0 (0.0%)	0 (0.0%)	3 (100.0%)	4 (100.0%)
	Diet/nutrition	0 (0.0%)	0 (0.0%)	2 (66.7%)	3 (75.0%)
	Exercise/physical activity	0 (0.0%)	0 (0.0%)	2 (66.7%)	3 (75.0%)
	Medicines	0 (0.0%)	0 (0.0%)	1 (33.3%)	2 (50.0%)
	Foot care and inspection	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (25.0%)
	Blood pressure	0 (0.0%)	0 (0.0%)	3 (100.0%)	4 (100.0%)
	Eye care and exams	0 (0.0%)	0 (0.0%)	3 (100.0%)	4 (100.0%)
	Lipid check	0 (0.0%)	0 (0.0%)	1 (33.3%)	2 (50.0%)
	Total valid response	0	0	3 (100.0%)	4 (100.0%)
	Total missing	2	0	1	4



Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Is there written information about diabetes available for patients in your main practice?	Yes, and information on eye complications is sufficient	0 (0.0%)	0 (0.0%)	1 (33.3%)	2 (50.0%)
	Yes, but information on eye complications is not sufficient	0 (0.0%)	0 (0.0%)	2 (66.7%)	2 (50.0%)
	Total Valid Response	0	0 (0.0%)	3 (100.0%)	4 (100.0%)
	Total missing	2	0	1	4

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Do you have written protocols/guidelines available in your main practice for the management of diabetes?	Yes, available and used by staff	0 (0.0%)	0 (0.0%)	1 (33.3%)	2 (50.0%)
	Yes, available but not used by staff	0 (0.0%)	0 (0.0%)	1 (33.3%)	1 (25.0%)
	Not available	0 (0.0%)	0 (0.0%)	1 (33.3%)	1 (25.0%)
	Total Valid Response	0	0 (0.0%)	3 (100.0%)	4 (100.0%)
	Total missing	2	0	1	4

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Do you have written protocols/guidelines for detection and management	Yes, available and used	0 (0.0%)	0 (0.0%)	2 (100.0%)	3 (100.0%)

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
of diabetes-related vision issue available in your main practice?	by staff				
	Total Valid Response	0	0 (0.0%)	2 (100.0%)	3 (100.0%)
	Total missing	2	0	2	5

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 (0.0%)	0 (0.0%)
	Mean		1		
	SD				
	Median				
	Min				
	Max				
	After a predetermined age (numeric response) (n)	0		0 (0.0%)	0 (0.0%)
	Mean		1		
	SD				
	Median				
	Min				
	Max				
	As soon as they are diagnosed			3 (100.0%)	4 (100.0%)
	Total valid response			3 (100.0%)	4 (100.0%)
	Total missing	2		1	4



Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
What is the protocol in your main practice for timing of initial eye exams for persons with diabetes - Type II?	After a predetermined number of years (numeric response) (n)	0		0 (0.0%)	0 (0.0%)
	Mean				
	SD				
	Median				
	Min				
	Max				
	After a predetermined age (numeric response) (n)	0		0 (0.0%)	0 (0.0%)
	Mean		1		
	SD				
	Median				
	Min				
	Max				
	As soon as they are diagnosed			3 (100.0%)	4 (100.0%)
	Total valid response			3 (100.0%)	4 (100.0%)
	Total missing	2		1	4

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
What is the protocol in your main practice for timing of follow-up eye examinations for persons with diabetes?	Once a year	0 (0.0%)	0 (0.0%)	1 (33.3%)	1 (25.0%)
	Every two years	0 (0.0%)	0 (0.0%)	2 (66.7%)	2 (50.0%)

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Other	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (25.0%)
	Total Valid Response	0	0 (0.0%)	3 (100.0%)	4 (100.0%)
	Total missing	2	0	1	4

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Do you screen patients for DR?	Yes			2 (50.0%)	2 (33.3%)
	No	1 (100.0%)		2 (50.0%)	4 (66.7%)
	Total valid response	1 (100.0%)		4 (100.0%)	6 (100.0%)
	Total missing	1			2
Where do you screen patients?	Outreach		-	1 (50.0%)	1 (50.0%)
	Other			1 (50.0%)	1 (50.0%)
	Total valid response			2 (100.0%)	2 (100.0%)
	Total missing	2		2	6

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
What patient characteristics influence your vision care and/or vision referrals?	Diabetes duration	0 (0.0%)	0 (0.0%)	2 (66.7%)	2 (66.7%)
	Patient's age	0 (0.0%)	0 (0.0%)	1 (33.3%)	1 (33.3%)
	Presence of comorbidities such as hypertension, etc.	0 (0.0%)	0 (0.0%)	3 (100.0%)	3 (100.0%)



Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	High glucose levels	0 (0.0%)	0 (0.0%)	3 (100.0%)	3 (100.0%)
	Patient adherence to recommendations	0 (0.0%)	0 (0.0%)	1 (33.3%)	1 (33.3%)
	Total valid response	0	0	3 (100.0%)	3 (100.0%)
	Total missing	2	0	1	5

# 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?	Long wait time for appointment	0 (0.0%)	0 (0.0%)	1 (33.3%)	1 (33.3%)
	Long wait time on the day of visit	0 (0.0%)	0 (0.0%)	1 (33.3%)	1 (33.3%)
	Referral process	0 (0.0%)	0 (0.0%)	1 (33.3%)	1 (33.3%)
	Lack of knowledge and/or awareness	0 (0.0%)	0 (0.0%)	1 (33.3%)	1 (33.3%)
	Patients fear of treatment/results	0 (0.0%)	0 (0.0%)	1 (33.3%)	1 (33.3%)
	Patients they are a burden on family/friends	0 (0.0%)	0 (0.0%)	1 (33.3%)	1 (33.3%)
	Patients feel eye complications are unlikely	0 (0.0%)	0 (0.0%)	1 (33.3%)	1 (33.3%)
	Patients feel eye exams are not important	0 (0.0%)	0 (0.0%)	2 (66.7%)	2 (66.7%)
	Total valid response	0	0	3 (100.0%)	3 (100.0%)
	Total missing	2	0	1	5

#### 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%)	0 (0.0%)	2 (66.7%)	2 (66.7%)
	No	0 (0.0%)	0 (0.0%)	1 (33.3%)	1 (33.3%)
	Total Valid Response	0	0 (0.0%)	3 (100.0%)	3 (100.0%)
	Total missing	2	0	1	5

#### PT 2.20

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Do you share relevant patient information with other health care professionals involved in the patients care e.g. his or her general practitioner, ophthalmologist, podiastrist?	Yes	0 (0.0%)	0 (0.0%)	2 (66.7%)	2 (66.7%)
	No	0 (0.0%)	0 (0.0%)	1 (33.3%)	1 (33.3%)
	Total Valid Response	0	0 (0.0%)	3 (100.0%)	3 (100.0%)
	Total missing	2	0	1	5

#### PT 3.1

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Please indicate your age:	30 - 39			1 (33.3%)	1 (33.3%)
	40 - 49			2 (66.7%)	2 (66.7%)
	Total valid response			3 (100.0%)	3 (100.0%)



Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Total missing	2		1	5
What is your gender?	Female		1	2 (66.7%)	2 (66.7%)
	Male			1 (33.3%)	1 (33.3%)
	Total valid response			3 (100.0%)	3 (100.0%)
	Total missing	2		1	5
What is your highest level of education completed?	Graduate or advanced degree (e.g. PhD, MD, etc)			3 (100.0%)	3 (100.0%)
	Total valid response			3 (100.0%)	3 (100.0%)
	Total missing	2		1	5

Question	Response	Ophthalmologist
What percentage of your patients have diabetic retinopathy	Total valid numeric response (n)	4
	Mean	13.0
	SD	14.5
	Median	11.0
	Min	0
	Max	30

Question	Response	Ophthalmologist
What percentage of your patients have diabetic macular edema?	Total valid numeric response (n)	4
	Mean	11.0
	SD	10.5
	Median	12.0
	Min	0
	Max	20

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?	More than 1 week but less than 1 month	1 (33.3%)
	More than 1 month but less than 2 months	1 (33.3%)
	More than 2 months but less than 3 months	1 (33.3%)
	Total Valid Response	3 (100.0%)
	Total missing	1

### PT 4.4

Question	Response	Ophthalmologist
From the time a patient is screened, what is the average length of time he/she waits for diagnosis?	Less than 1 week	1 (33.3%)
	More than 1 week but less than 1 month	1 (33.3%)
	There is not wait, diagnosis is given when screened	1 (33.3%)
	Total Valid Response	3 (100.0%)
	Total missing	1

Type of Treatment	Question	Response/time	Ophthalmologist
Laser photocoagulation	Is the treatment available?	Available within country	2 (66.7%)
	l	Available locally	2 (66.7%)
		Available in practice	1 (33.3%)
		Total valid response	3 (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)	2 (66.7%)



Type of Treatment	Question	Response/time	Ophthalmologist
		Mean	6.0
		SD	2.8
		Median	6.0
		Min	4
		Max	8
		Don't know/not sure	1 (33.3%)
		Total valid response	3 (100.0%)
		Total missing	1
	What is the average amount of time your patients wait for a first treatment?(weeks)	Total valid numeric response (n)	1 (50.0%)
		Mean	0.0
		SD	
		Median	0.0
		Min	0
		Max	0
		Don't know/not sure	1 (50.0%)
		Total valid response	2 (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)	2 (100.0%)
		Mean	10.0
		SD	8.5
		Median	10.0
		Min	4
		Max	16
		Total valid response	2 (100.0%)
		Total missing	2
Anti-VEGF therapies	Is the treatment available?	Available within country	2 (66.7%)
	1	Available locally	2 (66.7%)

Type of Treatment	Question	Response/time	Ophthalmologist
	1	Available in practice	1 (33.3%)
		Total valid response	3 (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)	2 (66.7%)
		Mean	6.0
		SD	2.8
		Median	6.0
		Min	4
		Max	8
		Don't know/not sure	1 (33.3%)
		Total valid response	3 (100.0%)
		Total missing	1
	What is the average amount of time your patients wait for a first treatment?(weeks)	Total valid numeric response (n)	1 (50.0%)
		Mean	1.0
		SD	
		Median	1.0
		Min	1
		Max	1
		Don't know/not sure	1 (50.0%)
		Total valid response	2 (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)	2 (100.0%)
		Mean	4.0
		SD	0.0
		Median	4.0



Type of Treatment	Question	Response/time	Ophthalmologist
		Min	4
		Max	4
		Total valid response	2 (100.0%)
		Total missing	2
Intravitreal steroid	Is the treatment available?	Available within country	2 (66.7%)
	-	Available locally	2 (66.7%)
		Available in practice	1 (33.3%)
		Total valid response	3 (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)	2 (66.7%)
		Mean	6.0
		SD	2.8
		Median	6.0
		Min	4
		Max	8
		Don't know/not sure	1 (33.3%)
		Total valid response	3 (100.0%)
		Total missing	1
	What is the average amount of time your patients wait for a first treatment?(weeks)	Total valid numeric response (n)	1 (50.0%)
		Mean	1.0
		SD	
		Median	1.0
		Min	1
		Max	1
		Don't know/not sure	1 (50.0%)
		Total valid	2 (100.0%)

Type of Treatment	Question	Response/time	Ophthalmologist
		response	
		Total missing	2
	What is the average amount of time your patients wait for a second treatment?(weeks)	Total valid numeric response (n)	2 (100.0%)
		Mean	8.0
		SD	5.7
		Median	8.0
		Min	4
		Max	12
		Total valid response	2 (100.0%)
		Total missing	2
Uncomplicated vitrectomy	Is the treatment available?	Available within country	2 (66.7%)
		Available locally	2 (66.7%)
		Available in practice	1 (33.3%)
		Total valid response	3 (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)	2 (66.7%)
		Mean	8.0
		SD	5.7
		Median	8.0
		Min	4
		Max	12
		Don't know/not sure	1 (33.3%)
		Total valid response	3 (100.0%)
		Total missing	1
	What is the average amount of time your patients wait for a first treatment?(weeks)	Total valid numeric response (n)	1 (50.0%)



Type of Treatment	Question	Response/time	Ophthalmologist
		Mean	8.0
		SD	
		Median	8.0
		Min	8
		Max	8
		Don't know/not sure	1 (50.0%)
		Total valid response	2 (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)	1 (50.0%)
		Mean	4.0
		SD	
		Median	4.0
		Min	4
		Max	4
		Don't know/not sure	1 (50.0%)
		Total valid response	2 (100.0%)
		Total missing	2
Complex vitreo- retinal surgery	Is the treatment available?	Available within country	2 (66.7%)
	1	Available locally	2 (66.7%)
		Available in practice	1 (33.3%)
		Total valid response	3 (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)	2 (66.7%)
		Mean	4.0
		SD	0.0
		Median	4.0

Type of Treatment	Question	Response/time	Ophthalmologist
		Min	4
		Max	4
		Don't know/not sure	1 (33.3%)
		Total valid response	3 (100.0%)
		Total missing	1
	What is the average amount of time your patients wait for a first treatment?(weeks)	Total valid numeric response (n)	1 (50.0%)
		Mean	4.0
		SD	
		Median	4.0
		Min	4
		Max	4
		Don't know/not sure	1 (50.0%)
		Total valid response	2 (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)	1 (50.0%)
		Mean	4.0
		SD	
		Median	4.0
		Min	4
		Max	4
		Don't know/not sure	1 (50.0%)
		Total valid response	2 (100.0%)
		Total missing	2

Question	Response	Ophthalmologist
Do you personally administer treatment for diabetic	Yes	3 (75.0%)



Question	Response	Ophthalmologist
retinopathy?		
	No	1 (25.0%)
	Total valid response	4 (100.0%)
Who administer it?	Total missing	4

Question	Response	Ophthalmologist
Do any of the following influence how you treat diabetic retinopathy or diabetic macular edema?	Diabetes duration	2 (66.7%)
	Patient's age	1 (33.3%)
	Presence of comorbidities such as hypertension, etc.	2 (66.7%)
	High glucose levels	2 (66.7%)
	Patient adherence to recommendations	1 (33.3%)
	Total valid response	3 (100.0%)
	Total missing	1

### PT 4.8

Question	Response	Ophthalmologist
Do you treat diabetic retinopathy and diabetic macular edema based on:	Visual outcome	1 (33.3%)
	Both	2 (66.7%)
	Total Valid Response	3 (100.0%)
	Total missing	1

Question	Response	Ophthalmologist
How are your patients with diabetes screened for diabetic eye disease?	Fundoscopy dilated	1 (33.3%)
	Retinal photo	3 (100.0%)
	Total valid response	3 (100.0%)

Question	Response	Ophthalmologist
	Total missing	1

Question	Response	Ophthalmologist
In your opinion, do the majority of your patients present:	In time for screening	3 (100.0%)
	Total Valid Response	3 (100.0%)
	Total missing	1

# PT 4.11

Question	Response	Ophthalmologist
Have you received training specifically on treatment and diagnosis of diabetic retinopathy and/or clinically significant diabetic macular edema?	Yes	3 (75.0%)
	No	1 (25.0%)
	Total valid response	4 (100.0%)
If yes, When was your last training?	Greater than 1 year ago but less than 5 years	1 (33.3%)
	Within the past year	2 (66.7%)
	Total valid response	3 (100.0%)
	Total missing	1

# PT 4.12

Question	Response	Ophthalmologist
Would you be interested in online education and certification on DME, Angiogenesis and Anti-VEGF therapies?	Yes	3 (75.0%)
	No	1 (25.0%)
	Total Valid Response	4 (100.0%)

Question	Response	Ophthalmologist
How is outreach for screening for diabetic eye disease done in your main practice?	Health fairs for people with diabetes	1 (50.0%)
	Mobile screening centers	1 (50.0%)
	Total valid response	2 (100.0%)



Question	Response	Ophthalmologist	
	Total missing	2	

Question	Response	Ophthalmologist
What do you perceive to be the greatest challenges for improving patient outcomes in diabetic eye disease?	Referral pathways	1 (33.3%)
	No universal guidelines on how to treat	1 (33.3%)
	Current available therapies not effective	1 (33.3%)
	Other	1 (33.3%)
	Total valid response	3 (100.0%)
	Total missing	1

#### EXP 1

Question	Response	Without DED (%)	With DED (%)	With DME (%)
Which of the following complications of diabetes do you have?	Cardiovascular disease/Stroke	1 (3.1%)	4 (12.5%)	2 (13.3%)
		-	I	I
	Irritable bowel disease	1 (3.1%)	3 (9.4%)	4 (26.7%)
	Kidney disease	1 (3.1%)	5 (15.6%)	4 (26.7%)
	Loss of feeling in hands or toes (neuropathy)	4 (12.5%)	9 (28.1%)	5 (33.3%)
	Vision loss	2 (6.3%)	3 (9.4%)	4 (26.7%)
	Foot ulcers	0 (0.0%)	1 (3.1%)	2 (13.3%)
	Amputation	1 (3.1%)	0 (0.0%)	2 (13.3%)
	Broken bones or fractures	1 (3.1%)	4 (12.5%)	0 (0.0%)
	None	20 (62.5%)	9 (28.1%)	1 (6.7%)
	Other	3 (9.4%)	10 (31.3%)	4 (26.7%)
	Don't know/Not sure	1 (3.1%)	2 (6.3%)	2 (13.3%)
	Total Valid Response	32 (100.0%)	32 (100.0%)	15 (100.0%)
	Total missing	7	0	0

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

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

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

## EXP 2

Limitations	Without DED n (%)	With DED n (%)	With DME n (%)
Limited in any way in any activities because of impairment or health problem	12 (44.4%)	21 (65.6%)	11 (73.3%)
Impairment or health problem			
Diabetes	9 (69.2%)	14 (66.7%)	8 (88.9%)
Back or neck problem	6 (54.5%)	10 (50.0%)	5 (55.6%)
Eye/vision problem	4 (40.0%)	8 (38.1%)	4 (44.4%)
Mental or emotional health	4 (36.4%)	8 (38.1%)	3 (37.5%)
Arthritis/rheumatism	3 (33.3%)	6 (30.0%)	0 (0.0%)
Hypertension/high blood pressure	2 (22.2%)	5 (25.0%)	4 (44.4%)
Walking problem	2 (20.0%)	9 (45.0%)	4 (44.4%)
Fractures, bone/joint injury	1 (12.5%)	7 (35.0%)	4 (44.4%)
Lung/breathing problem	1 (12.5%)	3 (15.0%)	0 (0.0%)
Stroke problem	1 (11.1%)	1 (5.0%)	0 (0.0%)
Cancer	0 (0.0%)	0 (0.0%)	1 (12.5%)
Hearing problem	0 (0.0%)	4 (20.0%)	0 (0.0%)
Heart problem	0 (0.0%)	4 (20.0%)	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".

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

#### EXP 3

Health Status	Without DED (%)	With DED (%)	With DME (%)
Self-rated health: Good	17 (63.0%)	11 (36.7%)	7 (50.0%)
Self-rated health: Poor	10 (37.0%)	19 (63.3%)	7 (50.0%)
Physically unhealthy days	13 (61.9%)	21 (77.8%)	9 (81.8%)
Mentally unhealthy days	13 (56.5%)	14 (51.9%)	8 (66.7%)
Unhealthy days	17 (77.3%)	21 (80.8%)	12 (100.0%)
Activity limitation days	7 (41.2%)	11 (47.8%)	6 (50.0%)

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

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

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

#### EXP 4



ltem	Response	All respondents	Respondents with Type I diabetes	Respondents with Type II diabetes
How do you manage your diabetes?	Diet	52 (63.4%)	46 (60.5%)	5 (100.0%)
	Oral medicine	16 (19.5%)	12 (15.8%)	4 (80.0%)
	Exercise	43 (52.4%)	39 (51.3%)	4 (80.0%)
	Insulin	79 (96.3%)	75 (98.7%)	3 (60.0%)
	Natural/Herbal medicine	3 (3.7%)	2 (2.6%)	1 (20.0%)

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

ltem	Response	Without DED (%)	With DED (%)	With DME (%)
Are you currently working?	Working for pay	13 (48.1%)	18 (56.3%)	6 (42.9%)
	Working without pay at home (e.g. housework, farming)	1 (3.7%)	2 (6.3%)	1 (7.1%)
	Retired	5 (18.5%)	7 (21.9%)	5 (35.7%)
	Student	4 (14.8%)	1 (3.1%)	1 (7.1%)
	Not working	4 (14.8%)	4 (12.5%)	1 (7.1%)
	Total Valid Response	27 (100.0%)	32 (100.0%)	14 (100.0%)
	Total missing	12	0	1
Do you receive assistance from the government?	Income assistance	3 (11.5%)	1 (3.6%)	1 (9.1%)
	Medical assistance	3 (11.5%)	2 (7.1%)	2 (18.2%)
	Food assistance	1 (3.8%)	2 (7.1%)	1 (9.1%)
	Housing assistance	2 (7.7%)	2 (7.1%)	2 (18.2%)
	Pension assistance	0 (0.0%)	1 (3.6%)	0 (0.0%)
	None of the above	20 (76.9%)	24 (85.7%)	8 (72.7%)
	Total valid response	26 (100.0%)	28 (100.0%)	11 (100.0%)
	Total missing	13	4	4
Did you have trouble paying for food at anytime during the past year?	Yes	5 (18.5%)	5 (15.6%)	5 (35.7%)

Item	Response	Without DED (%)	With DED (%)	With DME (%)
	No	22 (81.5%)	27 (84.4%)	9 (64.3%)
	Total Valid Response	27 (100.0%)	32 (100.0%)	14 (100.0%)
	Total missing	12	0	1

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	4 (40.0%)	10 (66.7%)	4 (57.1%)
	Working without pay at home (e.g. housework, farming)	1 (10.0%)	1 (6.7%)	0 (0.0%)
	Retired	1 (10.0%)	1 (6.7%)	1 (14.3%)
	Student	3 (30.0%)	1 (6.7%)	1 (14.3%)
	Not working	1 (10.0%)	2 (13.3%)	1 (14.3%)
	Total Valid Response	10 (100.0%)	15 (100.0%)	7 (100.0%)
	Total missing	3	0	0
Do you receive assistance from the government?	Income assistance	2 (20.0%)	1 (9.1%)	1 (16.7%)
	Medical assistance	2 (20.0%)	0 (0.0%)	1 (16.7%)
	Food assistance	1 (10.0%)	1 (9.1%)	1 (16.7%)
	Housing assistance	2 (20.0%)	2 (18.2%)	2 (33.3%)
	None of the above	6 (60.0%)	9 (81.8%)	4 (66.7%)
	Total valid response	10 (100.0%)	11 (100.0%)	6 (100.0%)
	Total missing	3	4	1
Did you have trouble paying for food at anytime during the past year?	Yes	2 (20.0%)	3 (20.0%)	4 (57.1%)
	No	8 (80.0%)	12 (80.0%)	3 (42.9%)
	Total Valid Response	10	15	7 (100.0%)



Item	Response	Without DED (%)	With DED (%)	With DME (%)
		(100.0%)	(100.0%)	
	Total missing	3	0	0

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

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

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

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

Item	Response	Without DED (%)	With DED (%)	With DME (%)
Are you currently working?	Working for pay	6 (66.7%)	8 (57.1%)	2 (50.0%)
	Working without pay at home (e.g. housework, farming)	0 (0.0%)	1 (7.1%)	0 (0.0%)
	Retired	0 (0.0%)	3 (21.4%)	2 (50.0%)
	Student	1 (11.1%)	0 (0.0%)	0 (0.0%)
	Not working	2 (22.2%)	2 (14.3%)	0 (0.0%)
	Total Valid Response	9 (100.0%)	14 (100.0%)	4 (100.0%)
	Total missing	4	0	1
Do you receive assistance from the government?	Medical assistance	1 (11.1%)	2 (14.3%)	1 (50.0%)
	Food assistance	0 (0.0%)	1 (7.1%)	0 (0.0%)
	Pension assistance	0 (0.0%)	1 (7.1%)	0 (0.0%)
	None of the above	8 (88.9%)	12 (85.7%)	1 (50.0%)
	Total valid response	9 (100.0%)	14 (100.0%)	2 (100.0%)
	Total missing	4	0	3
Did you have trouble paying for food at anytime during the past year?	Yes	2 (22.2%)	1 (7.1%)	1 (25.0%)
	No	7 (77.8%)	13 (92.9%)	3 (75.0%)
	Total Valid Response	9 (100.0%)	14 (100.0%)	4 (100.0%)
	Total missing	4	0	1

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

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

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

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

Item	Response	Without DED (%)	With DED (%)	With DME (%)
Are you currently working?	Working for pay	3 (37.5%)	0 (0.0%)	0 (0.0%)
	Working without pay at home (e.g. housework, farming)	0 (0.0%)	0 (0.0%)	1 (33.3%)
	Retired	4 (50.0%)	3 (100.0%)	2 (66.7%)
	Not working	1 (12.5%)	0 (0.0%)	0 (0.0%)
	Total Valid Response	8 (100.0%)	3 (100.0%)	3 (100.0%)
	Total missing	5	0	0
Do you receive assistance from the government?	Income assistance	1 (14.3%)	0 (0.0%)	0 (0.0%)
	None of the above	6 (85.7%)	3 (100.0%)	3 (100.0%)
	Total valid response	7 (100.0%)	3 (100.0%)	3 (100.0%)
	Total missing	6	0	0
Did you have trouble paying for food at anytime during the past year?	Yes	1 (12.5%)	1 (33.3%)	0 (0.0%)
	No	7 (87.5%)	2 (66.7%)	3 (100.0%)
	Total Valid Response	8 (100.0%)	3 (100.0%)	3 (100.0%)
	Total missing	5	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	EXP	5.5:	Age	group	80+ 1	vears
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Item	Response	Without DED (%)	With DED (%)	With DME (%)
Are you currently working?		0 (0.0%)	0 (0.0%)	0 (0.0%)
Do you receive assistance from the government?	Total valid response	0	0	0
	Total missing	0	0	0
Did you have trouble paying for food at anytime during the past year?		0 (0.0%)	0 (0.0%)	0 (0.0%)

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

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



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

#### EXP 6

Group	Subgroup	All respondents	Type 1 diabetes	Type 2 diabetes	With DED (%)	With DME (%)
All respondents		86 (100%)	79 (91.9%)	6 (7.0%)	32 (37.2%)	15 (17.4%)
Gender	Male	18 (24.0%)	15 (83.3%)	2 (11.1%)	4 (22.2%)	3 (16.7%)
	Female	57 (76.0%)	54 (94.7%)	3 (5.3%)	28 (49.1%)	12 (21.1%)
	Total Missing	11	10	1	0	0
Age	18-39 yrs	35 (40.7%)	35 (100.0%)	0 (0.0%)	15 (42.9%)	7 (20.0%)
	40-59 yrs	32 (37.2%)	27 (84.4%)	4 (12.5%)	14 (43.8%)	5 (15.6%)
	60-79 yrs	19 (22.1%)	17 (89.5%)	2 (10.5%)	3 (15.8%)	3 (15.8%)
Time since diagnosis	Within the last year	2 (2.3%)	1 (50.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	1 - 5 years ago	3 (3.5%)	1 (33.3%)	2 (66.7%)	0 (0.0%)	1 (33.3%)
	6 - 10 years ago	6 (7.0%)	6 (100.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	11 - 15 years ago	10 (11.6%)	9 (90.0%)	1 (10.0%)	5 (50.0%)	0 (0.0%)
	16 - 20 years ago	8 (9.3%)	7 (87.5%)	1 (12.5%)	3 (37.5%)	0 (0.0%)
	21 years ago or longer	56 (65.1%)	54 (96.4%)	2 (3.6%)	24 (42.9%)	14 (25.0%)
	Don't know/Not sure	1 (1.2%)	1 (100.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Control of Diabetes	Controlled	54 (65.1%)	48 (88.9%)	5 (9.3%)	20 (37.0%)	9 (16.7%)
	Not controlled	28 (33.7%)	27 (96.4%)	1 (3.6%)	11 (39.3%)	6 (21.4%)
	Don't know/Not sure	1 (1.2%)	1 (100.0%)	0 (0.0%)	1 (100.0%)	0 (0.0%)
	Total Missing	3	3	0	0	0

NB [1]: DED = respondents with DED ="Yes" minus respondents with DME ="Yes". NB [2]: DME = respondents with DME ="Yes".

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

# EXP 7

Question	Response	With DED n (%)	With DME n (%)
Have you had any treatment for diabetic eye disease?	Yes	17 (53.1%)	10 (71.4%)
	No	14 (43.8%)	4 (28.6%)
	Don't know/Not sure	1 (3.1%)	0 (0.0%)
	Total valid response	32 (100.0%)	14 (100.0%)
	Total missing	0	1
What treatment did you receive?	Laser	16 (100.0%)	10 (100.0%)
	Anti-VEGF	3 (18.8%)	3 (30.0%)
	Surgery	1 (6.3%)	5 (50.0%)
	Total valid response	16 (100.0%)	10 (100.0%)
	Total missing	16	5
Did you complete the treatment?	Yes	11 (64.7%)	8 (80.0%)
	Still receiving treatment	5 (29.4%)	2 (20.0%)
	Don't know/Not sure	1 (5.9%)	0 (0.0%)
	Total valid response	17 (100.0%)	10 (100.0%)
	Total missing	15	5
Do you feel that the treatment worked?	Yes, and vision improved	3 (17.6%)	4 (40.0%)
	Yes, but vision stayed the same	11 (64.7%)	5 (50.0%)
	Still waiting to know	2 (11.8%)	1 (10.0%)
	Don't know/Not sure	1 (5.9%)	0 (0.0%)
	Total valid response	17 (100.0%)	10 (100.0%)
	Total missing	15	5
What is/are the reason(s) that you did not complete the treatment?	Total valid response	0 (0.0%)	0 (0.0%)
	Total missing	32	15
What are the reason(s) that you have not had treatment for diabetic eye disease?	My doctor did not recommend any treatment	9 (69.2%)	3 (75.0%)
	Treatment is not accessible	1 (7.7%)	0 (0.0%)
	Treatment is not important to me	1 (7.7%)	0 (0.0%)



Question	Response	With DED n (%)	With DME n (%)
	Other	5 (38.5%)	1 (25.0%)
	Total valid response	13 (100.0%)	4 (100.0%)
	Total missing	19	11

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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