

The Diabetic Retinopathy Barometer Report

Sweden



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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 Sweden.

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 the three following 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

Sweden Study

Demographic Characteristics¹

Sweden is estimated to be the seventeenth most populous country in Europe with a population of approximately 9.8 million. According to the most recent statistics, it is estimated that ~17.5% of the population is under the age of 15 years and ~20% over the age of 65 years.

Despite Sweden currently having an ageing population, long life expectancy, and low fertility rates, the population is expected to increase by ~19% during the next few decades.

By 2050, it is expected that Sweden's population will be 11.8 million with those under the age of 15 years making up 17% of the total population and those aged 65 years and older will make up 24%.

Diabetes Profile²

Sweden has over 446,900 (368.9-676.0±) adults living with diabetes, which accounts to ~0.7% of people living with diabetes in this region. The diabetes national prevalence in Sweden (20 – 79 years) is 6.3 (5.2-9.5±) and the diabetes age-adjusted comparative prevalence is 4.7% (3.9-7.6±).

It is important to note that Sweden is 2nd in the world for the number of new cases of type 1 diabetes for people under 15 years of age at an estimated 43.2 cases per 100,000 population per year.

Deaths attributed to diabetes in Sweden in 2015 were 3,076, which accounts to ~0.5% of the diabetes-related deaths experienced in this region. The estimated number of undiagnosed cases was 168,700 (191.2-350.3±).

Study Populations: Sweden

As reported by 79 respondents with diabetes in Sweden, 5.1% were diagnosed with DED and a further 7.6% with DME.

Thirty-three health care professionals completed the survey in Sweden. Of these, four were diabetes specialist providers (12%), five were ophthalmologists (15%), and four were primary care providers (12%). The remaining respondents were either nurses, health educators or other types of professionals.

The DR Barometer Study: Sweden Overview

The DR Barometer study was conducted in 41 countries. In Sweden, 79 adults with diabetes and 33 health care professionals provided new information about the experiences of living with, managing and treating diabetes, DR and DME.

20%

of patients said that **being unlikely to have eye complications** was a barrier to eye exams



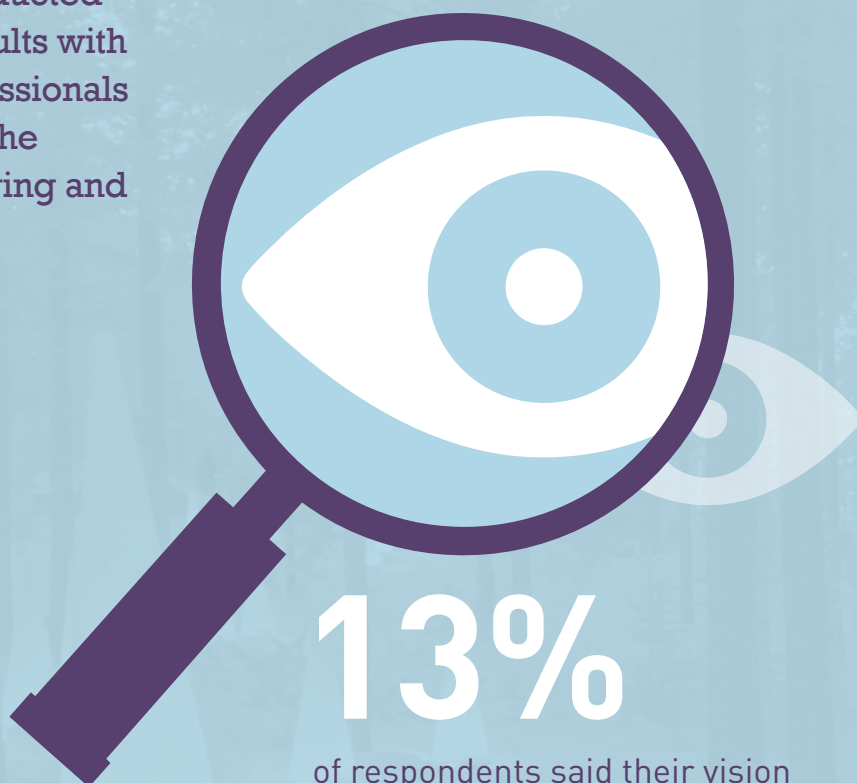
4%

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

DR: Diabetic Retinopathy

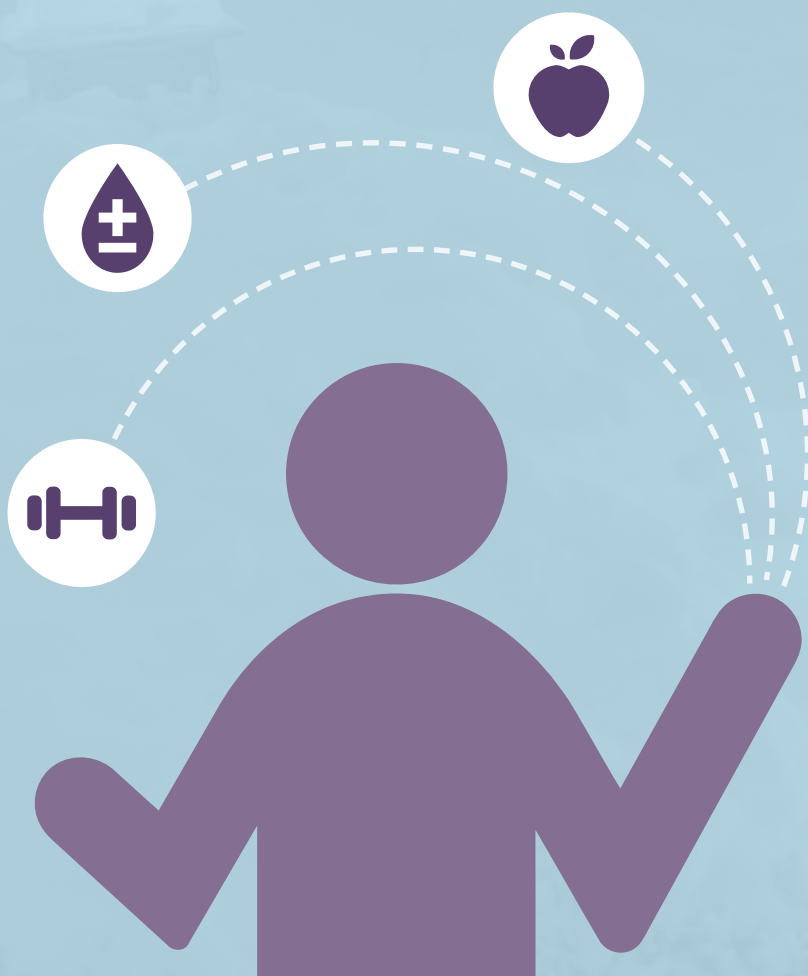
DME: Diabetic Macular Edema

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13%

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





100%

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



50%

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



25%

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

38%

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



Sweden

DR Barometer Findings:

Adults with Diabetes

Key Demographic Characteristics

Seventy-nine adults with diabetes completed the patients' survey in Sweden: 50% were female and 50% were male.

Sixty-five percent lived in an urban setting and 35% in a non-urban setting. The education levels of all respondents were as follows: 1.4% did not complete primary school, 17% were educated to a primary school level, 40% to a secondary school level, 33% to a college or university level, and 8.3% to a graduate or post-graduate level (see Appendix Table 4.2 and Table 4.3).

Twenty-three percent of all respondents were in paid employment, 60% were retired, and 7.1% were not working (see Appendix Table 4.4).

Most respondents (68%) were aged between 60 and 79 years (11% were 18-39 years, 17% were 40-59 years and 3.8% were 80 years and over). Twenty-eight percent were of traditional working age (18- 59 years) (see Table 1).

Of the respondents in Sweden, 22% had been diagnosed with type 1 diabetes and 76% with type 2 diabetes. A further 2.5% of respondents were either unsure of or did not know their type of diabetes (see Appendix Table 2.1). Five percent of respondents (n=4) had been diagnosed with DED and a further 7.6% (n=6) with DME.

Five percent of those surveyed were diagnosed with diabetes within the last year, 1 - 5 years ago (21%), 6 - 10 years ago (23%), 11 - 15 years ago (22%), 16 - 20 years ago (9.1%), and 21 years ago or more (17%) (see Appendix Table 2.2).

Amongst 18 to 39-year-olds, 78% had type 1 and 22% had type 2 diabetes. In the 40-59 age group almost one in three (31%) had type 1 and 69% had type 2, 9.3% of 60-79-year-olds had type 1 diabetes, and 87% had type 2.

In people aged 18-39 years, 22% had DED and 11% had DME. In those aged 40-59 years 7.7% had DED and 31% had DME and for people aged 60-79 years 1.9% had DED and 1.9% had DME.

Most (82%) respondents reported that their diabetes was well controlled, while 16% felt that this was not the case. For those who felt their diabetes was controlled, 4.8% had DED, and 4.8% had DME and where their condition was not well controlled 8.3% had DED and 17% had DME.

Table 1: Summary of key characteristics of adults with diabetes

Group	Subgroup	All Respondents	Type 1 diabetes	Type 2 diabetes	With DED	With DME
All respondents		79 (100.0%)	17 (21.5%)	60 (75.9%)	4 (5.1%)	6 (7.6%)
Gender	Male	36 (50.0%)	6 (16.7%)	29 (80.6%)	1 (2.8%)	0 (0.0%)
	Female	36 (50.0%)	11 (30.6%)	24 (66.7%)	3 (8.3%)	5 (13.9%)
	Total Missing	7	0	7	0	1
Age	18-39 yrs.	9 (11.4%)	7 (77.8%)	2 (22.2%)	2 (22.2%)	1 (11.1%)
	40-59 yrs.	13 (16.5%)	4 (30.8%)	9 (69.2%)	1 (7.7%)	4 (30.8%)
	60-79 yrs.	54 (68.4%)	5 (9.3%)	47 (87.0%)	1 (1.9%)	1 (1.9%)
	80 yrs. plus	3 (3.8%)	1 (33.3%)	2 (66.7%)	0 (0.0%)	0 (0.0%)
Time since diagnosis	Within the last year	4 (5.2%)	1 (25.0%)	3 (75.0%)	0 (0.0%)	1 (25.0%)
	1 - 5 yrs.	16 (20.8%)	3 (18.8%)	13 (81.3%)	1 (6.3%)	2 (12.5%)
	6 - 10 yrs.	18 (23.4%)	3 (16.7%)	14 (77.8%)	0 (0.0%)	1 (5.6%)
	11 - 15 yrs.	17 (22.1%)	2 (11.8%)	15 (88.2%)	1 (5.9%)	0 (0.0%)
	16 - 20 yrs.	7 (9.1%)	0 (0.0%)	7 (100.0%)	0 (0.0%)	0 (0.0%)
	21 yrs. plus	13 (16.9%)	8 (61.5%)	4 (30.8%)	2 (15.4%)	1 (7.7%)
	Don't know/ Not sure	2 (2.6%)	0 (0.0%)	2 (100.0%)	0 (0.0%)	1 (50.0%)
	Total Missing	2	0	2	0	0
Control of Diabetes	Controlled	63 (81.8%)	15 (23.8%)	46 (73.0%)	3 (4.8%)	3 (4.8%)
	Not controlled	12 (15.6%)	2 (16.7%)	10 (83.3%)	1 (8.3%)	2 (16.7%)
	Don't know/ Not sure	2 (2.6%)	0 (0.0%)	2 (100.0%)	0 (0.0%)	1 (50.0%)
	Total Missing	2	0	2	0	0

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

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

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

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

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

Knowledge and Management of Diabetes

Most (99%) of those surveyed saw a health care professional for their diabetes, with 43% seeing a diabetes specialist (average 2.4 times per year) and 40% seeing a general or family doctor (average 2.1 times per year) (see Appendix Table 2.3.1 and 2.3.2).

People were informed about their condition through a variety of channels. Eighty-eight percent received information from a doctor or nurse, 53% from a nutritionist or dietician and 33% from the internet (see Table 2 and Appendix Table 2.4).

Table 2: Source of information regarding diabetes

Information Source	All Respondents (n=77)
Doctor or nurse	68 (88.3%)
Nutritionist or dietician	41 (53.2%)
Internet	25 (32.5%)
Diabetes organisation or other health organisation	20 (26.0%)
TV/Radio/Newspaper/Magazines	17 (22.1%)
Family/Friends/Neighbours	8 (10.4%)
Pharmacist	6 (7.8%)
Social media (e.g. Facebook, Twitter, blogs)	3 (3.9%)
Health educator	2 (2.6%)
None of the above	1 (1.3%)

A range of strategies was used by respondents to manage their diabetes. For those with type 1 diabetes, apart from insulin, 35% managed their diabetes with exercise, 18% with diet and 5.9% with oral medicine. Of the respondents with type 2 diabetes, 79% reported that they managed their condition with oral medicine, 52% with exercise, 38% with insulin, and 28% with diet.

Only 13% were enrolled in diabetes management programmes and of these 70% 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 (95%), these occurred at less than 6 months (30%), 6 - 12 months (34%), and greater than 12 months (29%) (see Appendix Table 2.7).

The main challenges in controlling diabetes cited by respondents were: it was too hard to eat the right things (38%), the respondent didn't want to think about having diabetes (18%), long wait times for an appointment to see their doctor or specialist (13%), the respondent didn't know enough their condition (9.2%), and there were too many other things to do (9.2%) (see Appendix Table 2.9).

Free or low cost medicines or monitoring materials (57%), coordination of healthcare and services by a professional (40%), health education and information (25%), and support from family or friends (23%) were identified as important to improving the management of their diabetes (see Appendix Table 2.10).

Nature and Information about Complications

Almost all (90%) respondents were aware of vision loss and believed other complications, such as: foot ulcers (86%), neuropathy (72%), cardiovascular disease or stroke (71%), and amputation (68%) were associated with diabetes (see Appendix Table 2.11).

Patients were most concerned about vision loss (51%), cardiovascular disease or stroke (30%), amputation (3.9%), neuropathy (2.6%), and kidney disease (2.6%) (see Appendix Table 2.12).

Forty-six percent of respondents reported that they had no complications of diabetes. However, of those who did have complications 30% had neuropathy, vision loss (12%), cardiovascular disease or stroke (11%), foot ulcers (4.1%), and kidney disease (2.7%) (see Figure 1 and Appendix Table 2.13).

All people with DED and DME had complications with their condition (see Table 3 and EXP 1). Aside from vision loss, there was a considerable increase in the frequency of people with DED and DME experiencing complications compared to people without DED. For example, the frequency of those with neuropathy increased from 23% in those without DED to 75% with DED and 67% with DME.

Figure 1: Presence of complications

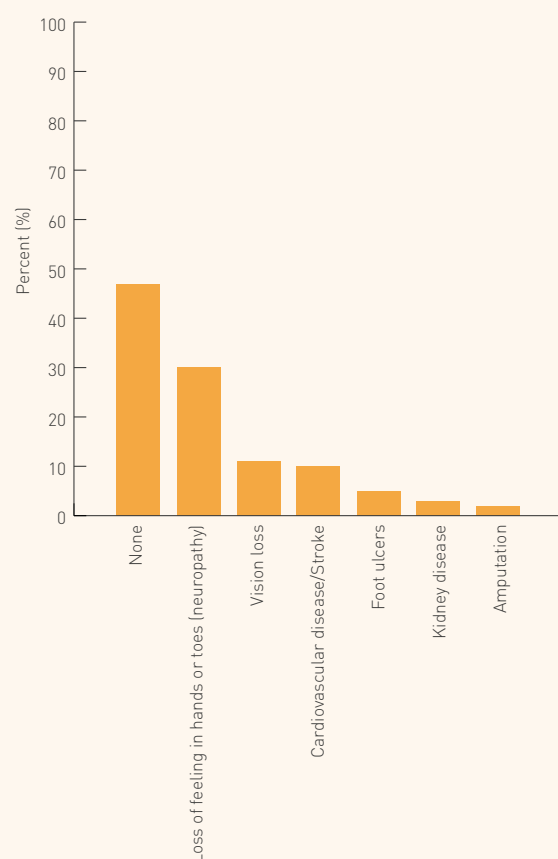


Table 3: Presence of complications without DED, with DED or DME

Complication	Without DED (n=64)	With DED (n=4)	With DME (n=6)
Any	30 (46.9%)	4 (100.0%)	6 (100.0%)
Loss of feeling in hands or toes (neuropathy)	15 (23.4%)	3 (75.0%)	4 (66.7%)
Vision loss	5 (7.8%)	1 (25.0%)	3 (50.0%)
Amputation	0 (0.0%)	1 (25.0%)	0 (0.0%)
Kidney disease	1 (1.6%)	0 (0.0%)	1 (16.7%)
Cardiovascular disease/Stroke	6 (9.4%)	0 (0.0%)	2 (33.3%)
Foot ulcers	3 (4.7%)	0 (0.0%)	0 (0.0%)
None	34 (53.1%)	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".

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

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

Information about Diabetic Eye Disease and Diabetic Macular Edema

Seventy percent of respondents said that eye complications were discussed with their health care professionals. Notwithstanding this, nearly 24% either never discussed eye complications with their provider or discussions only took place when symptoms arose (15%). The frequency of regular discussions varied from every visit (15%), multiple times a year (7.9%) and once a year (33%) (see Appendix Table 2.14).

Nearly three out of four patients (72%) reported that they did what they could to prevent vision problems (e.g. get routine screenings, visit specialists) yet 22% thought that vision problems were a normal part of ageing and 15% made no special effort to have a preventative approach to their eye health (see Appendix Table 2.15).

Thirty-seven percent of respondents had received information about DR and DME with a doctor or nurse being the most common source (22%). An important finding to note, 63% did not receive such information from any of the traditional sources listed (see Appendix Table 3.9).

Table 4: Source of information about DR and DME

Source	All respondents (n=68)
Doctor/Nurse	15 (22.1%)
Diabetes organisation or other health organisation	9 (13.2%)
Internet	8 (11.8%)
TV/Radio/Newspaper/Magazines	4 (5.9%)
Health educator	3 (4.4%)
Family/Friends/Neighbours	1 (1.5%)
None of the above	43 (63.2%)

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

Most (81%) respondents reported having an eye exam for DED, with 56% having the exam within the last year and a further 33% more than one year ago but less than two years ago (see Appendix Table 3.2).

Thirty-nine percent of respondents were aware of government sponsored screening programmes for DED (see Appendix Table 3.1).

While 41% of those surveyed thought they should have their eyes examined for DED once a year, 41% said that testing should only happen every two years and 12% said that it should happen less often than every two years. There was varied smaller number of respondents who thought testing should happen only when symptoms occur or not at all (see Appendix Table 3.4).

The biggest barriers to eye exams were that people felt they were not likely to have eye complications (20%), long wait times for an appointment (15%), and the referral process was complicated or took too long (15%) (see Table 5 and Appendix Table 3.5).

Table 5: Barriers to eye examinations

Identified Barriers	All Respondents (n=46)
I'm not likely to have eye complications	9 (19.6%)
Long wait time for appointment	7 (15.2%)
Referral process is complicated or takes too long	7 (15.2%)
Long wait time on the day of the visit	3 (6.5%)
Don't know much about my condition	3 (6.5%)
Limited access to diabetes specialists	3 (6.5%)
Too many other things to do or worry about	3 (6.5%)
Fear of treatment/results	2 (4.3%)
They are expensive	1 (2.2%)
Eye exams are not available near my home	1 (2.2%)
Recommended treatments for eye problems are not available	1 (2.2%)
Burden on my family/friends	1 (2.2%)
Other	18 (39.1%)

Treatment of Diabetic Eye Disease and Diabetic Macular Edema

Treatment was assessed separately in those with DED and DME.

Those with DED (75%) had received laser treatment (67%) and surgery (33%), which was ongoing for one of the respondents. Over two-thirds had completed treatment and 33% felt that it had been successful because their vision had stayed the same. Notably the number of respondents is extremely small (see Table 6).

For the respondent with DED (25%) who had not received treatment, the most common reason was that their doctor did not recommend treatment.

All patients with DME (n=6) had received treatment, with the most common being anti-VEGF (83%) and all felt that it had been successful and their vision stayed the same. Of those respondents with DME that had not completed their treatment (50%), the most common reason was that the eye doctor was located too far away (67%).

An unusual finding, there was a preference by most (67%) with DME was to have treatment when vision changes had occurred rather than to prevent further vision loss rather than a proactive approach (33%) (see Appendix Table 3.8).

Table 6: Treatment characteristics of patients with DED and DME

Question	Response	With DED (n=4)	With DME (n=6)
Have you had any treatment for diabetic eye disease?	Yes	3 (75.0%)	6 (100.0%)
	No	1 (25.0%)	0 (0.0%)
What treatment did you receive?	Laser	2 (66.7%)	1 (16.7%)
	Anti-VEGF	0 (0.0%)	5 (83.3%)
	Surgery	1 (33.3%)	1 (16.7%)
Did you complete the treatment?	Yes	2 (66.7%)	2 (33.3%)
	No	0 (0.0%)	3 (50.0%)
	Still receiving treatment	1 (33.3%)	1 (16.7%)
Do you feel that the treatment worked?	Yes, but vision stayed the same	1 (33.3%)	3 (100.0%)
	No	1 (33.3%)	0 (0.0%)
	Don't know/Not sure	1 (33.3%)	0 (0.0%)
What is/are the reason(s) that you did not complete the treatment?	Did not like the treatment	0 (0.0%)	1 (33.3%)
	Treatment was too expensive	0 (0.0%)	1 (33.3%)
	Eye doctor was located too far away	0 (0.0%)	2 (66.7%)
	Appointment times were not convenient	0 (0.0%)	1 (33.3%)
	Too much burden on my family/friends	0 (0.0%)	1 (33.3%)
What are the reason(s) that you have not had treatment for diabetic eye disease?	My doctor did not recommend any treatment	1 (100.0%)	0 (0.0%)
	Other	1 (100.0%)	0 (0.0%)

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

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

NB [3]: 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

Almost all (90%) of those diagnosed with DED or DME said that their vision was affected (30% significantly, 60% slightly) (see Appendix Table 3.6).

All of these respondents reported vision issues that impacted their daily lives in various ways such as difficulty driving a vehicle (50%), or having social interactions with family or friends (38%), undertaking household responsibilities, such as cooking or cleaning (25%), being involved with leisure activities or exercise (25%), working or keeping a job (13%), and managing their underlying diabetes (13%) (see Table 7).

Table 7: Activities affected through vision impairment and loss

	All Respondents (n=8)
Driving (a car/vehicle)	4 (50.0%)
Social interactions with family/friends	3 (37.5%)
Household responsibilities, such as cooking or cleaning	2 (25.0%)
Leisure activities/exercise	2 (25.0%)
Work or keeping a job	1 (12.5%)
Managing my diabetes	1 (12.5%)

Twenty-five percent of those with DED were in paid employment compared with 25% of respondents without DED (see Table 8 and EXP 5.1). Patients with vision complications reported difficulties with work or keeping a job (13%) and 25% of those with DED were not working.

Sixty-eight percent of those surveyed did not receive assistance from the government while 15% received medical assistance (see Appendix Table 4.5). A quarter (25%) of respondents without DED received assistance from the government as compared with 75% of those with DED and 80% with DME.

Ninety-two percent of all surveyed had no trouble paying for food at any time during the past year (see Appendix Table 4.6). The majority of respondents (82%) stated that they didn't feel access to healthcare was affected by any factors, while 6.1% reported that it was affected by age, 6.1% by gender and 6.1% by place of residence (see Appendix Table 4.7).

Forty-eight percent of those surveyed were worried about their health, 13% about family, while 16% were not worried about any of the items in the survey (see Appendix Table 4.8).

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

Question	Response	Without DED (n=61)	With DED (n=4)	With DME (n=5)
Are you currently working?	Working for pay	15 (24.6%)	1 (25.0%)	0 (0.0%)
	Working without pay at home (e.g. housework, farming)	0 (0.0%)	0 (0.0%)	2 (40.0%)
	Volunteering	1 (1.6%)	1 (25.0%)	2 (40.0%)
	Retired	40 (65.6%)	1 (25.0%)	1 (20.0%)
	Student	1 (1.6%)	0 (0.0%)	0 (0.0%)
	Not working	4 (6.6%)	1 (25.0%)	0 (0.0%)
Question	Response	Without DED (n=59)	With DED (n=4)	With DME (n=5)
Do you receive assistance from the government?	Income assistance	1 (1.7%)	0 (0.0%)	0 (0.0%)
	Medical assistance	7 (11.9%)	0 (0.0%)	3 (60.0%)
	Food assistance	0 (0.0%)	1 (25.0%)	1 (20.0%)
	Housing assistance	2 (3.4%)	1 (25.0%)	1 (20.0%)
	Pension assistance	6 (10.2%)	1 (25.0%)	0 (0.0%)
	None of the above	44 (74.6%)	1 (25.0%)	1 (20.0%)
Question	Response	Without DED (n=62)	With DED (n=4)	With DME (n=5)
Did you have trouble paying for food at any time during the past year?	Yes	1 (1.6%)	1 (25.0%)	4 (80.0%)
	No	61 (98.4%)	3 (75.0%)	1 (20.0%)

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

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

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

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

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

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).

Three quarters of people with DED and 20% with DME reported their health as poor compared to 34% of those without DED. For those without DED, 39% experienced physically unhealthy days and 19% mentally unhealthy days. In comparison, 33% of people with DED reported mentally unhealthy days and 50% with DME reported physically unhealthy days.

Compared with 41% of those without DED, 50% of people with DED and all with DME experienced limitations to their daily activities due to poor health. Where health impacted daily activities, the primary limitations were: diabetes, back or neck problems, hearing problems and hypertension or high blood pressure (see EXP 2).

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

Health Status	Without DED	With DED	With DME
Self-rated health: Good	40 (65.6%)	1 (25.0%)	4 (80.0%)
Self-rated health: Poor	21 (34.4%)	3 (75.0%)	1 (20.0%)
Physically unhealthy days	17 (38.6%)	0 (0.0%)	1 (50.0%)
Mentally unhealthy days	9 (18.8%)	1 (33.3%)	0 (0.0%)
Unhealthy days	21 (50.0%)	1 (33.3%)	1 (50.0%)
Activity limitation days	16 (50.0%)	0 (0.0%)	1 (100.0%)

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

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

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

NB [4]: 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.

Sweden

DR Barometer Findings:

Health Care Professionals

Key Demographic Characteristics

There were 33 health care professionals who answered at least one of the survey questions in Sweden. Of these, four were primary care providers (12%), four were diabetes specialist providers (12%) and five were ophthalmologists (15%). The remaining respondents were nurses, health educators or other professionals (see Appendix PT 1.3).

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

Health care professionals as a group had been practicing for an average of 21 years, with the ophthalmologist group practicing for an average of 17 years (see Appendix PT 1.5).

Providers were well educated (20% with graduate or advanced degree); 80% were female and 20% male, and 42% were aged 50 - 59 years, 27% in the 40-49 age group and 23% in the 60-69 age group (see Table 10 and Appendix PT 3.1).

Table 10: Summary of key characteristics of health care professionals

Group	Subgroup	All Respondents	Primary Care Provider	Diabetes Specialist	Ophthalmologist
All respondents		33 (100.0%)	4 (12.1%)	4 (12.1%)	5 (15.2%)
Age group	30 - 39 yrs.	2 (7.7%)	0 (0.0%)	1 (50.0%)	1 (20.0%)
	40 - 49 yrs.	7 (26.9%)	0 (0.0%)	0 (0.0%)	2 (40.0%)
	50 - 59 yrs.	11 (42.3%)	3 (75.0%)	0 (0.0%)	2 (40.0%)
	60 - 69 yrs.	6 (23.1%)	1 (25.0%)	1 (50.0%)	0 (0.0%)
Gender	Female	20 (80.0%)	3 (75.0%)	1 (100.0%)	2 (40.0%)
	Male	5 (20.0%)	1 (25.0%)	0 (0.0%)	3 (60.0%)
Education	College/University	20 (80.0%)	2 (50.0%)	1 (50.0%)	2 (50.0%)
	Graduate or advanced degree (e.g. PhD, MD, etc.)	5 (20.0%)	2 (50.0%)	1 (50.0%)	2 (50.0%)

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

Clinical Practice Characteristics

Half of the providers had their main practice in an eye clinic and for ophthalmologists only the settings were an eye clinic (80%) and hospital (20%). Most (84%) of the health care professionals worked in an urban setting (see Appendix PT 2.2 and PT 2.1).

About two-thirds (63%) of providers worked in the government sector while ophthalmologists worked in the government (40%), combined or mixed (40%), and private (20%) sectors (see Appendix PT 2.3).

Providers said that 83% of patients pay a reduced or subsidised rate for services, 17% pay out-of-pocket (full fees) and 10% pay some, and insurance pays some for services. The pattern was similar for ophthalmologists, where 80% of patients pay a reduced or subsidised rate for services, 20% pay through insurance for services and 20% pay some, and insurance pays some for services (see Appendix PT 2.7).

On average, all providers saw 60 patients per week with 58% (on average) with diabetes while ophthalmologists saw 73 patients per week and 28% had diabetes (see Appendix PT 2.6).

For all health care professionals, the average waiting time for an appointment was most commonly between two and six months (36%) and more than one week but less than one month (32%). For an appointment with an ophthalmologist, it was usually between three and six months in 60% of practices (see Appendix PT 2.5).

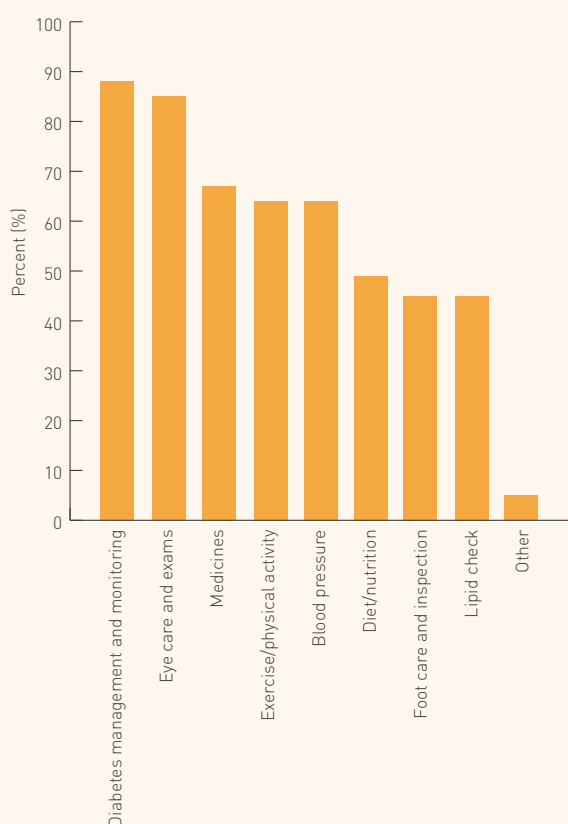
Table 11: Average wait times to schedule an appointment

Wait Time Intervals	All Respondents (n=28)	Ophthalmologist (n=5)
Less than 1 week	2 (7.1%)	0 (0.0%)
More than 1 week but less than 1 month	9 (32.1%)	0 (0.0%)
More than 1 month but less than 2 months	3 (10.7%)	1 (20.0%)
More than 2 months but less than 3 months	5 (17.9%)	1 (20.0%)
More than 3 months but less than 6 months	5 (17.9%)	3 (60.0%)
Other	2 (7.1%)	0 (0.0%)
Don't know/Not sure	2 (7.1%)	0 (0.0%)

Patient Education Information

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

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



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

Seventy-six percent of providers said that they had sufficient information about eye complications, 8% believed that the specific information was not sufficient and 8% said there was no information. All ophthalmologists (100%) had written information about diabetes and potential eye complications (see Table 12 and Appendix PT 2.11).

Guidelines and Protocols

Ninety-two percent of providers and all ophthalmologists had written protocols for the management of diabetes, which were used by staff (see Appendix PT 2.12).

With respect to the management of diabetes-related vision issues, 69% of health care professionals and all ophthalmologists had written protocols and these were used by staff. A small proportion of providers (3.8%) did not have the specific protocols (see Appendix PT 2.13).

Table 12: Availability and use of information and protocols

Question	Response	All Respondents (n=25)	Ophthalmologist (n=5)
Is there written information about diabetes available for patients in your main practice?	Yes, and information on eye complications is sufficient	19 (76.0%)	5 (100.0%)
	Yes, but information on eye complications is not sufficient	2 (8.0%)	0 (0.0%)
	Yes, but no information on eye complications is included	2 (8.0%)	0 (0.0%)
	No written information is available for patients	2 (8.0%)	0 (0.0%)
Question	Response	All Respondents (n=26)	Ophthalmologist (n=5)
Do you have written protocols/guidelines for detection and management of diabetes-related vision issue available in your main practice?	Yes, available and used by staff	18 (69.2%)	5 (100.0%)
	Not available	1 (3.8%)	0 (0.0%)
	Don't know/Not sure	7 (26.9%)	0 (0.0%)

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

Screening Protocols and Barriers in the Care Pathway

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

The initial eye exam was recommended for either type 1 and type 2 diabetes at the time of diagnosis by 52% and 92% of providers respectively (see Appendix PT 2.14).

Overall, fifteen percent of health care professionals and all ophthalmologists reported that follow-up eye examinations were conducted every year. All ophthalmologists and 70% of health care professionals screen patients for DR (see Appendix PT 2.15 and PT 2.16).

Across all health care professionals, 89% send appointment reminders. Seventy-seven percent of the health care professionals and all 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 professionals and ophthalmologists respectively were: diabetes duration (56%) (80%), high glucose levels (56%) (80%), presence of comorbidities such as hypertension (44%) (80%), a patient's age (28%) (40%), and a patient's gender (4%) (20%) (see Appendix PT 2.17).

As reported by health care professionals, the major barriers to optimising eye health were the limited access to eye specialists (48%), patients feeling that eye exams were not important (36%), and patients have competing responsibilities and priorities (28%) (see Table 13 and Appendix PT 2.18).

Ophthalmologists like health care professionals reported similar barriers with the addition that some clinics were too small or lacked the necessary equipment or staff (50%). Notably the number of respondents is extremely small (n=4).

Table 13: Major barriers to optimising eye health

Response	All Respondents (n=25)	Ophthalmologists (n=4)
Limited access to eye specialists	12 (48.0%)	4 (100.0%)
Clinic too small or lack necessary equipment/staff	2 (8.0%)	2 (50.0%)
Long wait time for appointment	4 (16.0%)	1 (25.0%)
Long wait time on the day of visit	3 (12.0%)	1 (25.0%)
Limited access to diabetes specialists	2 (8.0%)	1 (25.0%)
Patients have competing responsibilities and priorities	7 (28.0%)	1 (25.0%)
Cost of care	1 (4.0%)	0 (0.0%)
Proximity to care	2 (8.0%)	0 (0.0%)
Lack of knowledge and/or awareness	6 (24.0%)	0 (0.0%)
Patients fear of treatment/results	5 (20.0%)	0 (0.0%)
Patients feel eye complications are unlikely	2 (8.0%)	0 (0.0%)
Patients feel eye exams are not important	9 (36.0%)	0 (0.0%)
Other	9 (36.0%)	1 (25.0%)

Sweden

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 19% of patients seen by the ophthalmologist had DR and 8% DME (see Appendix PT 4.1 and PT 4.2).

The most common waiting times for a screening appointment for DED was between two and three months (50%) and six or more months (50%) (see Appendix PT 4.3).

Fifty percent of ophthalmologists reported a wait time from screening to diagnosis of less than one week, and one said that the wait time was more than one week but less than one month (see Appendix PT 4.4).

Treatment and Challenges

Seventy-five percent of ophthalmologists personally administer treatment for DR and the most common factors influencing treatment were: the presence of comorbidities such as hypertension (100%), duration of diabetes (67%), and high glucose levels (67%) (see Appendix PT 4.6 and PT 4.7).

The most common outreach venues for screening for DED were health fairs for people with diabetes (25%) and mobile screening centres (25%) (see Appendix PT 4.13).

All ophthalmologists reported that they screen patients for DR based on retinal photo. Additionally 75% use fundoscopy through dilated pupils, 75% use optical coherence tomography, 50% use fluorescein angiography, and 25% use fundoscopy through undilated pupils. Fifty percent treat DR and DME based on both visual and anatomical outcomes (see Appendix PT 4.8 and PT 4.9).

All ophthalmologists (n=4) reported that patients present “in time” for screening (see Appendix PT 4.10).

Seventy-five percent of ophthalmologists had received specific training on the treatment and diagnosis of DR and or DME. Sixty-seven percent had training within the past year and 33% more than between one and five years ago. All would be interested in online education and certification on DME, angiogenesis and anti-VEGF therapies (see Appendix PT 4.11 and PT 4.12).

The greatest challenge as perceived by the ophthalmologist for improving patient outcomes in DED were the complex and sometimes inadequate referral pathways (see Table 14 and PT 4.14).

Table 14: Challenges for improving patient outcomes in DED

Question	Response	Ophthalmologist (n=3)
What do you perceive to be the greatest challenges for improving patient outcomes in diabetic eye disease?	Referral pathways	2 (66.7%)
	Late diagnosis	1 (33.3%)
	No universal guidelines on referral/screening	1 (33.3%)
	No universal guidelines on how to treat	1 (33.3%)
	No universal guideline on when to treat	1 (33.3%)
	Other	1 (33.3%)

Sweden

DR Barometer Summary

In Sweden, 79 adults with diabetes and 33 health care professionals provided insight about their experiences of living with, managing and treating diabetes, DR and DME.

The results of the DR Barometer Study, Sweden 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.

Even though Sweden today has a large ageing population, long life expectancy, and low fertility rates, its population is expected to increase by ~19% during the next few decades. By 2050, it is expected that there will be 11.8 million inhabitants with those under the age of 15 years making up 17% of the total population and those aged 65 years and older accounting for 24% of the total population.

Alongside the demographic changes, the prevalence of people with diabetes is climbing rapidly. Sweden has over 446,900 (368.9-676.0±) adults living with diabetes with the reputation of having the second highest number of new cases of type 1 diabetes for people under 15 years of age in the world at an estimated 43.2 cases per 100,000 population per year in the world.

Deaths attributed to diabetes in Sweden in 2015 were 3,076, which accounts for ~0.5% of the diabetes-related deaths experienced in this region and there are some 168,700 (191.2-350.3±) undiagnosed cases.

The DR Barometer findings indicate that overall a younger population was more likely to be associated with type 1 diabetes, which was the opposite for those with type 2 diabetes, which tended to be an older population. Seventy-eight percent of those in the youngest age group (18-39 years) had type 1 diabetes (22% type 2). In the 40 – 59 age group 31% had type 1 (69% type 2) and in the 60-79 age group 9.3% had type 1 (87% type 2).

People were most often informed about their condition by health professionals such as the doctor, nurse, and nutritionist. Diabetes and other health organisations, and TV, radio, newspapers or magazines also played important roles and were viewed as valuable sources of information. A trend globally and reflected in the Sweden study, was the increasing use of the internet by 32% of the respondents.

Only 13% of respondents were enrolled in diabetes management programmes and 70% 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. Yet some respondents did not want to think about having diabetes while others did not know enough about their condition. In addition for some surveyed the long wait times for an appointment was a challenge.

There was a relatively high awareness of the complications associated with diabetes. Vision loss (51%) was by far the most concerning followed by cardiovascular disease (30%) then amputation (3.9%). While nearly half of those surveyed had no complications there was still many who reported having neuropathy, vision loss, and cardiovascular disease. Though the number of respondents was small, all those with DED and DME had an increased frequency of certain complications compared with those without DED, for example the frequency of neuropathy increased from 23% in those without DED to 75% with DED and 67% with DME.

Knowing that diabetic-related vision loss is preventable addressing barriers to eye screening is an important policy issue. While most respondents had received an eye exam, which is understandable considering the purposeful sample, there remained many personal and systemic barriers such as respondents saying that they didn't think that they were likely to have eye complications, long wait times for an appointment and the referral process was complicated or was too long.

Evidence shows that the relationship between the patient and the health care professional is critical to ensure realistic and optimal patient outcomes. It was therefore surprising that nearly a quarter of patients surveyed had either never had a conversation about eye complications with their health professional or it only took place only when symptoms were present. Equally concerning is the myths and perceptions around vision changes with more than 22% of patients saying that vision problems were a normal part of ageing and 15% not making any special effort to prevent vision problems.

Almost all (90%) of those with DED or DME said that their vision was slightly or significantly affected which in turn impacted their health, lifestyle, and life choices including difficulty in driving a vehicle, social interactions with friends and family, undertaking household responsibilities, such as cooking or cleaning and leisure activities.

A small number of respondents reported that their access to healthcare was affected by their age, gender, and where they actually lived.

Patient education is very much at the heart of a proactive approach so it was gratifying to know that about three-quarters of providers had written information on diabetes and eye complications with only a relatively small percentage reporting that the section on eye complications was either insufficient or non-existent. Also more than two-thirds (69%) of providers and ophthalmologists had 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 52% and 92% of all providers respectively said that an initial eye exam should occur at time of the diagnosis of diabetes and there was agreement by most that follow-up eye examinations should be conducted annually.

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

Limited access to eye specialists and some clinics being too small or lacking the necessary equipment and staff were viewed by health care professionals as some of the greatest challenges for improving patient outcomes in DED.

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

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

References and Acknowledgement

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

² International Diabetes Federation. (2015). *IDF Diabetes Atlas*. Accessed from: <http://www.diabetesatlas.org/>

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

Appendices

The Diabetic Retinopathy Barometer Survey: Appendices for Sweden

APPENDIX 1 : National Results

Table 1.1

Survey Information	Number of Respondents (%)
All valid respondents [1]	95 (100.0%)
Respondents aged 18 or over	94 (98.9%)
Respondents with diabetes	79 (83.2%)

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

Table 1.2

Survey Information	Number of Respondents (%)
All valid respondents	95 (100.0%)
Included in Diabetic Analysis Set	79 (83.2%)
Excluded from Diabetic Analysis Set	16 (16.8%)
Reasons for exclusion from diabetic analysis set	.
Under 18 years of age	1
Not diagnosed with diabetes	14
Missing information on diabetes diagnosis	1

Table 1.3

Survey Information	Number of Respondents (%)
Diabetic Analysis Set	79 (100.0%)
World Bank Income Group: High Income	79 (100.0%)
Persons with diabetic eye disease (DED)	4 (5.1%)
Persons with diabetic macular edema (DME)	6 (7.6%)
Persons with Type I diabetes	17 (21.5%)
Persons with Type II diabetes	60 (75.9%)
Persons not seeing health care professional for diabetes	1 (1.3%)
Persons seeing health care professional for diabetes	76 (96.2%)
Persons with eye disease & not received treatment	1 (1.3%)
Persons with eye disease & received treatment	9 (11.4%)

Table 2.1

Question	Response	Number of Respondents (%)
With which type of diabetes have you been diagnosed?	Type I	17 (21.5)
	Type II	60 (75.9)
	Don't know/Not sure	2 (2.5)
	Total Valid Response	79 (100.0)

Table 2.2

Question	Response	Number of Respondents (%)
When was your diabetes diagnosed?	Within the last year	4 (5.2)
	1 - 5 years ago	16 (20.8)
	6 - 10 years ago	18 (23.4)
	11 - 15 years ago	17 (22.1)
	16 - 20 years ago	7 (9.1)
	21 years ago or longer	13 (16.9)
	Don't know/Not sure	2 (2.6)
	Total Valid Response	77 (100.0)
	Total missing	2

Table 2.3.1

Question	Response	Number of Respondents (%)
Do you see a health care professional for your diabetes?	Yes	76 (98.7)
	No	1 (1.3)
	Total Valid Response	77 (100.0)
	Total missing	2
What kind of health care professional?	General/Family Doctor	30 (39.5)
	Nurse	13 (17.1)
	Diabetes Specialist	33 (43.4)
	Total Valid Response	76 (100.0)

Question	Response	Number of Respondents (%)
	Total missing	3

Table 2.3.2

Type of health care professional	Times per year seen for diabetes	Value
General/Family Doctor	Total valid numeric response (n)	30
	Mean	2.1
	SD	1.0
	Median	2.0
	Min	1
	Max	5
Nurse	Total valid numeric response (n)	9
	Mean	2.0
	SD	0.5
	Median	2.0
	Min	1
	Max	3
	Don't know/Not sure	1
	Total missing	3
Diabetes Specialist	Total valid numeric response (n)	27
	Mean	2.4
	SD	1.1
	Median	2.0
	Min	1
	Max	5
	Don't know/Not sure	1
	Total missing	5

Table 2.4

Question	Response	Number of Respondents (%)
How have you received information about diabetes?	Doctor or nurse	68 (88.3%)

Question	Response	Number of Respondents (%)
	Health educator	2 (2.6%)
	Nutritionist or dietitian	41 (53.2%)
	Diabetes organization or other health organization	20 (26.0%)
	Family/Friends/Neighbors	8 (10.4%)
	TV/Radio/Newspaper/Magazines	17 (22.1%)
	Internet	25 (32.5%)
	Social media (e.g. Facebook, Twitter, blogs)	3 (3.9%)
	Pharmacist	6 (7.8%)
	None of the above	1 (1.3%)
	Total Valid Response	77 (100.0%)
	Total missing	2

Table 2.5

Question	Response	Number of Respondents (%)
How do you manage your diabetes?	Diet	20 (26.0%)
	Oral medicine	47 (61.0%)
	Exercise	37 (48.1%)
	Insulin	40 (51.9%)
	Total Valid Response	77 (100.0%)
	Total missing	2

Table 2.6

Question	Response	Number of Respondents (%)
Are you currently enrolled in a diabetes patient management support programme?	Yes	10 (13.0)
	No	67 (87.0)
	Total Valid Response	77 (100.0)
	Total missing	2
Who sponsors the programme?	Hospital support program	2 (20.0)
	Clinic support program	2 (20.0)

Question	Response	Number of Respondents (%)
	Pharmaceutical support program	3 (30.0)
	Patient organization support program	2 (20.0)
	Don't know/Not sure	1 (10.0)
	Total Valid Response	10 (100.0)
	Total missing	69
Does the programme include education on the importance of screening for diabetic eye complications?	Yes	7 (70.0)
	No	3 (30.0)
	Total Valid Response	10 (100.0)
	Total missing	69

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	72 (93.5%)
	Less than 6 months	61 (79.2%)
	6 - 12 months	10 (13.0%)
	Total valid response	71 (92.2%)
	Total missing	8
	No	5 (6.5%)
	Total valid response	77 (100.0%)
	Total missing	2
Urine check	Yes	73 (94.8%)
	Less than 6 months	50 (64.9%)
	6 - 12 months	16 (20.8%)
	Greater than 12 months	6 (7.8%)

Test	Response	Number of Respondents (%)
Have you ever had the following tests in a doctors office of clinic? And if yes, how long ago		
	Total valid response	72 (93.5%)
	Total missing	7
	No	3 (3.9%)
	Don't know/Not sure	1 (1.3%)
	Total valid response	77 (100.0%)
	Total missing	2
Weight check	Yes	72 (93.5%)
	Less than 6 months	45 (58.4%)
	6 - 12 months	22 (28.6%)
	Greater than 12 months	4 (5.2%)
	Total valid response	71 (92.2%)
	Total missing	8
	No	5 (6.5%)
	Total valid response	77 (100.0%)
	Total missing	2
Blood pressure check	Yes	69 (92.0%)
	Less than 6 months	54 (72.0%)
	6 - 12 months	14 (18.7%)
	Greater than 12 months	1 (1.3%)
	Total valid response	69 (92.0%)
	Total missing	10
	No	5 (6.7%)
	Don't know/Not sure	1 (1.3%)
	Total valid	75 (100.0%)

Test	Response	Number of Respondents (%)
Have you ever had the following tests in a doctors office of clinic? And if yes, how long ago		
	response	
	Total missing	4
Foot check	Yes	68 (89.5%)
	Less than 6 months	39 (51.3%)
	6 - 12 months	18 (23.7%)
	Greater than 12 months	10 (13.2%)
	Total valid response	67 (88.2%)
	Total missing	12
	No	8 (10.5%)
	Total valid response	76 (100.0%)
	Total missing	3
Eye check	Yes	72 (94.7%)
	Less than 6 months	23 (30.3%)
	6 - 12 months	26 (34.2%)
	Greater than 12 months	22 (28.9%)
	Total valid response	71 (93.4%)
	Total missing	8
	No	3 (3.9%)
	Don't know/Not sure	1 (1.3%)
	Total valid response	76 (100.0%)
	Total missing	3

Table 2.8

Question	Response	Number of Respondents (%)
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Question	Response	Number of Respondents (%)
How well do you think your diabetes is controlled?	Very well	21 (27.3%)
	Well	42 (54.5%)
	Not very well	12 (15.6%)
	Don't know/Not sure	2 (2.6%)
	Total Valid Response	77 (100.0%)
	Total missing	2

Table 2.9

Question	Response	Number of Respondents (%)
What are the main challenges you face in controlling your diabetes?	High cost of care	2 (2.6%)
	No insurance	3 (3.9%)
	Long wait time for an appointment to see my doctor or specialist	10 (13.2%)
	Health services needed are not available	5 (6.6%)
	Don't know enough about diabetes	7 (9.2%)
	Too hard to eat the right things	29 (38.2%)
	Too many other things to do	7 (9.2%)
	Stigma or discrimination because of diabetes	1 (1.3%)
	Don't want to think about having diabetes	14 (18.4%)
	Other	7 (9.2%)
	Total Valid Response	76 (100.0%)
	Total missing	3

Table 2.10

Question	Response	Number of Respondents (%)
Which of the following services currently help you better manage your diabetes?	Free or low cost medicines or monitoring materials	44 (57.1%)

Question	Response	Number of Respondents (%)
	Support groups	3 (3.9%)
	Support from family or friends	18 (23.4%)
	Health education and information	19 (24.7%)
	Mobile services (services that travel to or near your home)	3 (3.9%)
	Coordination of healthcare and services by a professional	31 (40.3%)
	Emergency helpline	3 (3.9%)
	Other	3 (3.9%)
	None	15 (19.5%)
	Total Valid Response	77 (100.0%)
	Total missing	2

Table 2.11

Question	Response	Number of Respondents (%)
What complications (or problems), to your knowledge, arise from diabetes?	Amputation	52 (68.4%)
	Foot ulcers	65 (85.5%)
	Increased risk of broken bones or fractures	19 (25.0%)
	Loss of feeling in hands or toes (neuropathy)	55 (72.4%)
	Vision loss	68 (89.5%)
	Irritable bowel disease	12 (15.8%)
	Kidney disease	45 (59.2%)
	Cardiovascular disease/Stroke	54 (71.1%)
	Other	2 (2.6%)
	Don't know/Not sure	1 (1.3%)
	None	3 (3.9%)
	Total Valid Response	76 (100.0%)
	Total missing	3

Table 2.12

Question	Response	Number of Respondents (%)
Which complication of diabetes are you most concerned about?	Amputation	3 (3.9)
	Foot ulcers	1 (1.3)
	Loss of feeling in hands or toes (neuropathy)	2 (2.6)
	Vision loss	39 (51.3)
	Kidney disease	2 (2.6)
	Cardiovascular disease/Stroke	23 (30.3)
	Don't know/Not sure	5 (6.6)
	None	1 (1.3)
	Total Valid Response	76 (100.0)
	Total missing	3

Table 2.13

Question	Response	Number of Respondents (%)
Which of the following complications of diabetes do you have?	Amputation	1 (1.4%)
	Foot ulcers	3 (4.1%)
	Broken bones or fractures	3 (4.1%)
	Loss of feeling in hands or toes (neuropathy)	22 (29.7%)
	Vision loss	9 (12.2%)
	Irritable bowel disease	4 (5.4%)
	Kidney disease	2 (2.7%)
	Cardiovascular disease/Stroke	8 (10.8%)
	Don't know/Not sure	6 (8.1%)
	None	34 (45.9%)
	Total Valid Response	74 (100.0%)
	Total missing	5

Table 2.14

Question	Response	Number of Respondents (%)
How often do you discuss the possibility of eye	Every visit	11 (14.5%)

Question	Response	Number of Respondents (%)
complications with your health care professional?		
	Multiple times per year	6 (7.9%)
	Once per year	25 (32.9%)
	Only when symptoms arise	11 (14.5%)
	Never	18 (23.7%)
	Don't know/Not sure	5 (6.6%)
	Total Valid Response	76 (100.0%)
	Total missing	3

Table 2.15

Question	Response	Number of Respondents (%)
Which of the following best describes your attitude to vision issues?	I think that vision problems are a normal part of ageing	17 (22.4%)
	I do what I can to prevent vision problems (e.g. get routine screenings, visit specialists)	55 (72.4%)
	I do not make any special effort to prevent vision problems	11 (14.5%)
	Total Valid Response	76 (100.0%)
	Total missing	3

Table 2.16

Question	Response	Number of Respondents (%)
What type of health insurance do you have?	Public	52 (68.4)
	Public - Private	13 (17.1)
	Private	3 (3.9)
	None	8 (10.5)
	Total Valid Response	76 (100.0)
	Total missing	3

Table 2.17

Question	Response	Number of Respondents (%)
Most often, how do you pay for the following types of medical care and services?		
General doctor visits (e.g. primary care doctor)	Care is free	7 (9.3)
	Insurance pays total cost	2 (2.7)
	Insurance and out-of-pocket/cash (e.g. co-pays)	29 (38.7)
	Out-of-pocket only (pay cash for all care)	37 (49.3)
	Total Valid Response	75 (100.0)
	Total missing	4
Specialist medical visits (e.g. eye doctor, gynecologist, urologist)	Care is free	6 (8.0)
	Insurance pays total cost	1 (1.3)
	Insurance and out-of-pocket/cash (e.g. co-pays)	29 (38.7)
	Out-of-pocket only (pay cash for all care)	35 (46.7)
	Do not use service	2 (2.7)
	Don't know/Not Sure	2 (2.7)
	Total Valid Response	75 (100.0)
	Total missing	4
Medicines	Care is free	16 (21.9)
	Insurance pays total cost	4 (5.5)
	Insurance and out-of-pocket/cash (e.g. co-pays)	26 (35.6)
	Out-of-pocket only (pay cash for all care)	27 (37.0)
	Total Valid Response	73 (100.0)
	Total missing	6
Medical supplies (e.g. blood glucose meter/strips)	Care is free	51 (68.9)
	Insurance pays total cost	3 (4.1)
	Insurance and out-of-pocket/cash (e.g. co-pays)	6 (8.1)
	Out-of-pocket only (pay cash for all care)	8 (10.8)

Question	Response	Number of Respondents (%)
Most often, how do you pay for the following types of medical care and services?		
	Do not use service	6 (8.1)
	Total Valid Response	74 (100.0)
	Total missing	5
Procedures	Care is free	6 (8.1)
	Insurance pays total cost	3 (4.1)
	Insurance and out-of-pocket/cash (e.g. co-pays)	27 (36.5)
	Out-of-pocket only (pay cash for all care)	33 (44.6)
	Do not use service	3 (4.1)
	Don't know/Not Sure	2 (2.7)
	Total Valid Response	74 (100.0)
	Total missing	5
Tests/screenings	Care is free	19 (27.5)
	Insurance pays total cost	4 (5.8)
	Insurance and out-of-pocket/cash (e.g. co-pays)	21 (30.4)
	Out-of-pocket only (pay cash for all care)	21 (30.4)
	Do not use service	1 (1.4)
	Don't know/Not Sure	3 (4.3)
	Total Valid Response	69 (100.0)
	Total missing	10
Health education	Care is free	12 (18.8)
	Insurance and out-of-pocket/cash (e.g. co-pays)	5 (7.8)
	Out-of-pocket only (pay cash for all care)	13 (20.3)
	Do not use service	29 (45.3)
	Don't know/Not Sure	5 (7.8)
	Total Valid Response	64 (100.0)
	Total missing	15
Counseling	Care is free	21 (31.8)

Question	Response	Number of Respondents (%)
Most often, how do you pay for the following types of medical care and services?		
	Insurance pays total cost	1 (1.5)
	Insurance and out-of-pocket/cash (e.g. co-pays)	9 (13.6)
	Out-of-pocket only (pay cash for all care)	16 (24.2)
	Do not use service	14 (21.2)
	Don't know/Not Sure	5 (7.6)
	Total Valid Response	66 (100.0)
	Total missing	13

Table 3.1

Question	Response	Number of Respondents (%)
Are you aware of any government sponsored screening programs for diabetic eye disease (diabetic retinopathy)?	Yes	28 (38.9%)
	No	44 (61.1%)
	Total valid response	72 (100.0%)
	Total missing	7

Table 3.2

Question	Response	Number of Respondents (%)
Have you ever had an eye exam for diabetic eye disease?	Yes	61 (81.3%)
	No	14 (18.7%)
	Total valid response	75 (100.0%)
	Total missing	4
How long ago was your last eye exam?	Within the last year	34 (55.7%)
	More than 1 year ago but less than 2 years	20 (32.8%)
	More than 2 years ago but less than 3 years	7 (11.5%)
	Total valid response	61 (100.0%)

Question	Response	Number of Respondents (%)
	Total missing	18
Who did the last exam?	General/Family practitioner	4 (6.6%)
	Eye doctor/Eye clinic	53 (86.9%)
	Other	4 (6.6%)
	Total valid response	61 (100.0%)
	Total missing	18

Table 3.3

Question	Response	Number of Respondents (%)
Have you ever had a dilated eye exam, where your eyes are examined after eye drops?	Yes	68 (91.9%)
	No	6 (8.1%)
	Total valid response	74 (100.0%)
	Total missing	5

Table 3.4

Question	Response	Number of Respondents (%)
Based on what you know, how often should you get your eyes examined for diabetic eye disease?	Once a year	31 (41.3%)
	Every two years	31 (41.3%)
	Less often than every two years	9 (12.0%)
	Only when symptoms occur	1 (1.3%)
	Never	1 (1.3%)
	Don't know/Not sure	2 (2.7%)
	Total valid response	75 (100.0%)
	Total missing	4

Table 3.5

Question	Response	Number of Respondents (%)
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Question	Response	Number of Respondents (%)
For you, what are the biggest barriers to eye exams?	They are expensive	1 (2.2%)
	Eye exams are not available near my home	1 (2.2%)
	Long wait time for appointment	7 (15.2%)
	Long wait time on the day of the visit	3 (6.5%)
	Referral process is complicated or takes too long	7 (15.2%)
	Recommended treatments for eye problems are not available	1 (2.2%)
	Don't know much about my condition	3 (6.5%)
	Fear of treatment/results	2 (4.3%)
	Burden on my family/friends	1 (2.2%)
	Limited access to diabetes specialists	3 (6.5%)
	I'm not likely to have eye complications	9 (19.6%)
	Too many other things to do or worry about	3 (6.5%)
	Other	18 (39.1%)
	Total valid response	46 (100.0%)
	Total missing	33

Table 3.6

Question	Response	Number of Respondents (%)
Have you been diagnosed with diabetic eye disease?	Yes	10 (13.7%)
	No	63 (86.3%)
	Total valid response	73 (100.0%)
	Total missing	6
Has your diabetic eye disease affected your vision?	Yes, slightly	6 (60.0%)
	Yes, significantly	3 (30.0%)
	No	1 (10.0%)
	Total valid response	10 (100.0%)
	Total missing	69

Question	Response	Number of Respondents (%)
Have vision issues caused you to have difficulty with any of the following?	Household responsibilities, such as cooking or cleaning	2 (25.0%)
	Social interactions with family/friends	3 (37.5%)
	Leisure activities/exercise	2 (25.0%)
	Work or keeping a job	1 (12.5%)
	Managing my diabetes	1 (12.5%)
	Driving (a car/vehicle)	4 (50.0%)
	Total valid response	8 (100.0%)
	Total missing	71

Table 3.7

Question	Response	Number of Respondents (%)
Have you had any treatment for diabetic eye disease?	Yes	9 (90.0%)
	No	1 (10.0%)
	Total valid response	10 (100.0%)
	Total missing	69
What treatment did you receive?	Laser	3 (33.3%)
	Injection in the eye (Anti-VEGF)	5 (55.6%)
	Surgery	2 (22.2%)
	Total valid response	9 (100.0%)
	Total missing	70
Did you complete the treatment?	Yes	4 (44.4%)
	No	3 (33.3%)
	Still receiving treatment	2 (22.2%)
	Total valid response	9 (100.0%)
	Total missing	70
Do you feel that the treatment worked?	Yes, but vision stayed the same	4 (66.7%)
	No	1 (16.7%)
	Don't know/Not sure	1 (16.7%)
	Total valid response	6 (100.0%)

Question	Response	Number of Respondents (%)
	Total missing	73
What is/are the reason(s) that you did not complete the treatment?	Did not like the treatment	1 (33.3%)
	Treatment was too expensive	1 (33.3%)
	Eye doctor was located too far away	2 (66.7%)
	Appointment times were not convenient	1 (33.3%)
	Too much burden on my family/friends	1 (33.3%)
	Total valid response	3 (100.0%)
	Total missing	76
What are the reason(s) that you have not had treatment for diabetic eye disease?	My doctor did not recommend any treatment	1 (100.0%)
	Total valid response	1 (100.0%)
	Total missing	78

Table 3.8

Question	Response	Number of Respondents (%)
Have you been diagnosed with diabetic macular edema?	Yes	6 (8.2%)
	No	58 (79.5%)
	Don't know/Not sure	9 (12.3%)
	Total valid response	73 (100.0%)
	Total missing	6
If Yes, which of the following would you prefer	Treatment to prevent further vision loss	2 (33.3%)
	Only treatment when vision loss has occurred	4 (66.7%)
	Total valid response	6 (100.0%)
	Total missing	73

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	15 (22.1%)
	Health educator	3 (4.4%)
	Diabetes organization or other health organization	9 (13.2%)
	Family/Friends/Neighbors	1 (1.5%)
	TV/Radio/Newspaper/Magazines	4 (5.9%)
	Internet	8 (11.8%)
	None of the above	43 (63.2%)
	Total valid response	68 (100.0%)
	Total missing	11

Table 4.1

Question	Response	Number of Respondents (%)
What is your gender?	Female	36 (50.0)
	Male	36 (50.0)
	Total Valid Response	72 (100.0)
	Total missing	7
Please indicate your age	18 - 29	6 (7.6)
	30 - 39	3 (3.8)
	40 - 49	6 (7.6)
	50 - 59	7 (8.9)
	60 - 69	21 (26.6)
	70 - 79	33 (41.8)
	80 - 89	3 (3.8)
	Total Valid Response	79 (100.0)

Table 4.2

Question	Response	Number of Respondents (%)
Where do you live?	Urban setting	47 (65.3)
	Non-urban setting	25 (34.7)
	Total Valid Response	72 (100.0)

Question	Response	Number of Respondents (%)
	Total missing	7

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	12 (16.7)
	Secondary school	29 (40.3)
	College/University	24 (33.3)
	Graduate or post-graduate	6 (8.3)
	Total valid response	72 (100.0)
	Total missing	7

Table 4.4

Question	Response	Number of Respondents (%)
Are you currently working?	Working for pay	16 (22.9)
	Working without pay at home (e.g. housework, farming)	2 (2.9)
	Volunteering	4 (5.7)
	Retired	42 (60.0)
	Student	1 (1.4)
	Not working	5 (7.1)
	Total Valid Response	70 (100.0)
	Total missing	9

Table 4.5

Question	Response	Number of Respondents (%)
Do you receive assistance from the government?	Income assistance	1 (1.5%)
	Medical assistance	10 (14.7%)
	Food assistance	2 (2.9%)
	Housing assistance	4 (5.9%)

Question	Response	Number of Respondents (%)
	Pension assistance	7 (10.3%)
	None of the above	46 (67.6%)
	Total valid response	68 (100.0%)
	Total missing	11

Table 4.6

Question	Response	Number of Respondents (%)
Did you have trouble paying for food at anytime during the past year?	Yes	6 (8.5)
	No	65 (91.5)
	Total Valid Response	71 (100.0)
	Total missing	8

Table 4.7

Question	Response	Number of Respondents (%)
Do you feel that your access to health care is negatively affected by any of the following?	Age	4 (6.1)
	Ethnicity	1 (1.5)
	Gender	4 (6.1)
	Income	1 (1.5)
	Language you speak	1 (1.5)
	Place of birth	1 (1.5)
	Place where you live	4 (6.1)
	Race	2 (3.0)
	Religion	2 (3.0)
	Tribal affiliation	2 (3.0)
	None of the above	54 (81.8)
	Total valid response	66 (100.0)

Question	Response	Number of Respondents (%)
	Total missing	13

Table 4.8

Question	Response	Number of Respondents (%)
Which of the following do you worry about most?	Housing	4 (5.6)
	Money	13 (18.3)
	Health	34 (47.9)
	Family	9 (12.7)
	None of the above	11 (15.5)
	Total Valid Response	71 (100.0)
	Total missing	8

Table 5.1

Question	Response	Number of Respondents (%)
In general, would you say your health is:	Very good	8 (11.4%)
	Good	37 (52.9%)
	Total good health	45 (64.3%)
	Fair	20 (28.6%)
	Poor	5 (7.1%)
	Fair or poor health	25 (35.7%)
	Total valid response	70 (100.0%)
	Total missing	9

Table 5.2

Question	Response	Number of Respondents (%)
How many days during last 30 days was your physical health not good	Any unhealthy days	18 (37.5%)
	1-5 unhealthy days	7 (14.6%)
	6-10 unhealthy days	5 (10.4%)

Question	Response	Number of Respondents (%)
	21-30 unhealthy days	6 (12.5%)
	No unhealthy days	30 (62.5%)
	Total valid response	48 (100.0%)
	Total missing	31

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	10 (18.5%)
	1-5 unhealthy days	6 (11.1%)
	6-10 unhealthy days	1 (1.9%)
	11-20 unhealthy days	1 (1.9%)
	21-30 unhealthy days	2 (3.7%)
	No unhealthy days	44 (81.5%)
	Total valid response	54 (100.0%)
	Total missing	25

Table 5.3.2

Question	Response	Number of Respondents (%)
Unhealthy days (physically or mentally unhealthy, max 30)	Any unhealthy days	23 (48.9%)
	1-5 unhealthy days	8 (17.0%)
	6-10 unhealthy days	5 (10.6%)
	11-20 unhealthy days	2 (4.3%)
	21-30 unhealthy	8 (17.0%)

Question	Response	Number of Respondents (%)
	days	
	No unhealthy days	24 (51.1%)
	Total valid response	47 (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	17 (51.5%)
	1-5 unhealthy days	7 (21.2%)
	6-10 unhealthy days	4 (12.1%)
	11-20 unhealthy days	5 (15.2%)
	21-30 unhealthy days	1 (3.0%)
	No unhealthy days	16 (48.5%)
	Total valid response	33 (100.0%)
	Total missing	46

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	32 (51.6%)
	No	30 (48.4%)
	Total valid response	62 (100.0%)
	Total missing	17
Which impairment or health problem, if any, limits your activities?		
a) Arthritis/rheumatism	Yes	11 (34.4%)

Question	Response	Number of Respondents (%)
	No	20 (62.5%)
	Don't know/Not sure	1 (3.1%)
	Total valid response	32 (100.0%)
	Total missing	47
b) Back or neck problem	Yes	19 (54.3%)
	No	14 (40.0%)
	Don't know/Not sure	2 (5.7%)
	Total valid response	35 (100.0%)
	Total missing	44
c) Fractures, bone/joint injury	Yes	4 (13.3%)
	No	26 (86.7%)
	Total valid response	30 (100.0%)
	Total missing	49
d) Walking problem	Yes	9 (30.0%)
	No	19 (63.3%)
	Don't know/Not sure	2 (6.7%)
	Total valid response	30 (100.0%)
	Total missing	49
e) Lung/breathing problem	Yes	8 (26.7%)
	No	20 (66.7%)
	Don't know/Not sure	2 (6.7%)
	Total valid response	30 (100.0%)
	Total missing	49
f) Hearing problem	Yes	14 (45.2%)
	No	17 (54.8%)
	Total valid response	31 (100.0%)

Question	Response	Number of Respondents (%)
	Total missing	48
g) Eye/vision problem	Yes	13 (39.4%)
	No	18 (54.5%)
	Don't know/Not sure	2 (6.1%)
	Total valid response	33 (100.0%)
	Total missing	46
h) Heart problem	Yes	5 (16.1%)
	No	25 (80.6%)
	Refused	1 (3.2%)
	Total valid response	31 (100.0%)
	Total missing	48
i) Stroke problem	Yes	3 (9.7%)
	No	27 (87.1%)
	Refused	1 (3.2%)
	Total valid response	31 (100.0%)
	Total missing	48
j) Hypertension/high blood pressure	Yes	14 (43.8%)
	No	17 (53.1%)
	Don't know/Not sure	1 (3.1%)
	Total valid response	32 (100.0%)
	Total missing	47
k) Diabetes	Yes	23 (67.6%)
	No	10 (29.4%)
	Don't know/Not sure	1 (2.9%)
	Total valid response	34 (100.0%)
	Total missing	45
l) Cancer	Yes	3 (9.4%)

Question	Response	Number of Respondents (%)
	No	28 (87.5%)
	Don't know/Not sure	1 (3.1%)
	Total valid response	32 (100.0%)
	Total missing	47
m) Mental or emotional health	Yes	7 (21.2%)
	No	22 (66.7%)
	Don't know/Not sure	3 (9.1%)
	Refused	1 (3.0%)
	Total valid response	33 (100.0%)
	Total missing	46

PT 1.2

Analysis Sets	Number of Respondents (%)
All valid respondents	33 (100.0%)
Included in Provider Analysis Set (PAS)	33 (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	33
Included in the Eye Care Professional Set (Eye Specialist)	5 (15.2%)
Excluded in the Eye Care Professional Set (Eye Specialist)	28 (84.8%)
Reasons for exclusion from Eye Care Professional Set:	
Missing required speciality	28
No valid (non-missing) response for the supplemental eye questionnaire	0

PT 1.3

Subgroups	Number of Respondents (%)
Provider Analysis Set	33 (100.0%)

Subgroups	Number of Respondents (%)
Primary Care Provider	4 (12.1%)
Diabetes Specialist Provider	4 (12.1%)
Eye Care Professional	5 (15.2%)
Ophthalmologist	5 (15.2%)

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	4 (100.0%)	0 (0.0%)	0 (0.0%)	4 (12.1%)
	Diabetes specialist	0 (0.0%)	4 (100.0%)	1 (20.0%)	5 (15.2%)
	General ophthalmologist	0 (0.0%)	0 (0.0%)	4 (80.0%)	4 (12.1%)
	Optometrist	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	Retinal specialist	0 (0.0%)	0 (0.0%)	3 (60.0%)	3 (9.1%)
	Nurse	0 (0.0%)	1 (25.0%)	1 (20.0%)	21 (63.6%)
	Health educator	0 (0.0%)	2 (50.0%)	0 (0.0%)	2 (6.1%)
	None of the above	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (3.0%)
	Total valid response	4 (100.0%)	4 (100.0%)	5 (100.0%)	33 (100.0%)
	Total missing	0	0	0	0

PT 1.5

Item	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
How long have you been practicing in this profession?	Total valid response (n)	4	3	5	32
	Mean	21.0	14.3	16.8	21.3
	SD	16.6	12.9	10.5	11.2
	Median	22.0	18.0	14.0	23.5

Item	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Min.	0	0	5	0
	Max.	40	25	32	40
	Total missing	0	1	0	1

PT 2.1

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
What is your main practice setting?	Diabetes clinic/practice	0 (0.0%)	0 (0.0%)	0 (0.0%)	3 (9.4%)
	Eye clinic/practice	0 (0.0%)	1 (33.3%)	4 (80.0%)	16 (50.0%)
	General medical clinic/practice	4 (100.0%)	1 (33.3%)	0 (0.0%)	7 (21.9%)
	Hospital	0 (0.0%)	1 (33.3%)	1 (20.0%)	6 (18.8%)
	Other	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	Other	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	Total Valid Response	4 (100.0%)	3 (100.0%)	5 (100.0%)	32 (100.0%)
	Total missing	0	1	0	1

PT 2.2

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Where is your main practice located?	Urban setting	4 (100.0%)	2 (66.7%)	4 (80.0%)	27 (84.4%)
	Non-urban setting	0 (0.0%)	1 (33.3%)	1 (20.0%)	5 (15.6%)
	Total Valid Response	4 (100.0%)	3 (100.0%)	5 (100.0%)	32 (100.0%)
	Total missing	0	1	0	1

PT 2.3

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
In which sector is your main practice?	Government	2 (50.0%)	2 (66.7%)	2 (40.0%)	20 (62.5%)
	Private	2 (50.0%)	1 (33.3%)	1 (20.0%)	8 (25.0%)
	Non profit	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	Combined/mixed	0 (0.0%)	0 (0.0%)	2 (40.0%)	4 (12.5%)
	Total Valid Response	4 (100.0%)	3 (100.0%)	5 (100.0%)	32 (100.0%)
	Total missing	0	1	0	1

PT 2.4

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Is your main practice limited to certain populations?	No	4 (100.0%)	3 (100.0%)	4 (80.0%)	26 (81.3%)
	Yes, limited by age	0 (0.0%)	0 (0.0%)	1 (20.0%)	6 (18.8%)
	Yes, other	0 (0.0%)	0 (0.0%)	1 (20.0%)	1 (3.1%)
	Total valid response	4 (100.0%)	3 (100.0%)	5 (100.0%)	32 (100.0%)
	Total missing	0	1	0	1

PT 2.5

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
What is the average wait time for an appointment in your main practice?	Less than 1 week	2 (50.0%)	0 (0.0%)	0 (0.0%)	2 (7.1%)
	More than 1 week but less than 1 month	2 (50.0%)	1 (100.0%)	0 (0.0%)	9 (32.1%)
	More than 1 month but less	0 (0.0%)	0 (0.0%)	1 (20.0%)	3 (10.7%)

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	than 2 months				
	More than 2 months but less than 3 months	0 (0.0%)	0 (0.0%)	1 (20.0%)	5 (17.9%)
	More than 3 months but less than 6 months	0 (0.0%)	0 (0.0%)	3 (60.0%)	5 (17.9%)
	Other	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (7.1%)
	Don't know/Not sure	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (7.1%)
	Total Valid Response	4 (100.0%)	1 (100.0%)	5 (100.0%)	28 (100.0%)
	Total missing	0	3	0	5

PT 2.6

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
On average, how many patients do you see per week in your main practice [n patients]	Total valid response (n)	4	1	5	26
	Mean	61.3	35	73.4	59.5
	SD	10.3	.	18	37.8
	Median	60	35	70	51
	Min.	50	35	52	20
	Max.	75	35	100	200
	Total missing	0	3	0	7
What percentage of the patients in your main practice have diabetes [% patients]	Total valid response (n)	4	1	5	26
	Mean	11.3	98	28	58.4
	SD	12.6	.	16.8	35.6
	Median	6	98	25	55

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Min.	3	98	10	3
	Max.	30	98	50	100
	Total missing	0	3	0	7

PT 2.7

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
In your main practice, how do patients pay for the care and services that you provide?	Don't pay	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (6.9%)
	Pay a reduced/subsidized rate	4 (100.0%)	0 (0.0%)	4 (80.0%)	24 (82.8%)
	Pay out-of-pocket (full fees)	0 (0.0%)	1 (50.0%)	0 (0.0%)	5 (17.2%)
	Pay through insurance	0 (0.0%)	0 (0.0%)	1 (20.0%)	2 (6.9%)
	Patient pays some, insurance pays some	0 (0.0%)	1 (50.0%)	1 (20.0%)	3 (10.3%)
	Other	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (3.4%)
	Total valid response	4 (100.0%)	2 (100.0%)	5 (100.0%)	29 (100.0%)
	Total missing	0	2	0	4

PT 2.8

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
In addition to your main practice, do you work in another practice setting?	Yes	1 (25.0%)			2 (6.7%)
	No	3 (75.0%)	3 (100.0%)	5 (100.0%)	28 (93.3%)

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Total valid response	4 (100.0%)	3 (100.0%)	5 (100.0%)	30 (100.0%)
	Total missing		1		3
In which other practice setting(s) do you work?	Eye clinic/practice				1 (50.0%)
	Other	1 (100.0%)			1 (50.0%)
	Total valid response	1 (100.0%)			2 (100.0%)
	Total missing	3	4	5	31
In which sector(s) is(are) the practice(s)?	Government	1 (100.0%)			2 (100.0%)
	Total valid response	1 (100.0%)			2 (100.0%)
	Total missing	3	4	5	31
Is there a major difference between your practices with respect to how diabetic eye disease is screened and managed?	No	1 (100.0%)			2 (100.0%)
	Total valid response	1 (100.0%)			2 (100.0%)
	Total missing	3	4	5	31

PT 2.9

Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Blood glucose	Yes		4 (100.0%)	1 (100.0%)	1 (25.0%)	10 (52.6%)
	Total valid numeric response (n)	4 (100.0%)		0 (0.0%)	1 (25.0%)	7 (36.8%)
	Mean	3.0			2.0	2.9
	SD	1.2				1.1
	Median	3.0			2.0	2.0
	Min	2			2	2

Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
		Max	4		2	4
		Total missing	0	4	4	26
	No				3 (75.0%)	9 (47.4%)
	Total valid response	4 (100.0%)			1 (100.0%)	4 (100.0%)
	Total missing				3	1
HbA1c	Yes		4 (100.0%)	1 (100.0%)	1 (25.0%)	13 (65.0%)
		Total valid numeric response (n)	4 (100.0%)	0 (0.0%)	1 (25.0%)	10 (50.0%)
		Mean	2.5		1.0	2.6
		SD	1.0			1.0
		Median	2.0		1.0	2.5
		Min	2		1	1
		Max	4		1	4
		Total missing	0	4	4	23
	No				3 (75.0%)	7 (35.0%)
	Total valid response	4 (100.0%)			1 (100.0%)	4 (100.0%)
	Total missing				3	1
Urine check	Yes		4 (100.0%)	1 (100.0%)		11 (57.9%)
			4 (100.0%)	1 (100.0%)	0 (0.0%)	9 (47.4%)
		Mean	2.5	1.0		1.7
		SD	1.0			1.0
		Median	2.0	1.0		1.0
		Min	2	1		1

Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
		Max	4	1		4
		Total missing	0	3	5	24
	No				3 (100.0%)	8 (42.1%)
	Total valid response		4 (100.0%)	1 (100.0%)	3 (100.0%)	19 (100.0%)
	Total missing			3	2	14
Weight check	Yes		4 (100.0%)	1 (100.0%)	1 (25.0%)	13 (65.0%)
		Total valid numeric response (n)	4 (100.0%)	0 (0.0%)	1 (25.0%)	10 (50.0%)
		Mean	2.5		2.0	2.4
		SD	1.0			0.7
		Median	2.0		2.0	2.0
		Min	2		2	2
		Max	4		2	4
		Total missing	0	4	4	23
	No				3 (75.0%)	7 (35.0%)
	Total valid response		4 (100.0%)	1 (100.0%)	4 (100.0%)	20 (100.0%)
	Total missing			3	1	13
Blood pressure check	Yes		4 (100.0%)	1 (100.0%)	2 (50.0%)	14 (70.0%)
		Total valid numeric response (n)	4 (100.0%)	0 (0.0%)	2 (50.0%)	11 (55.0%)
		Mean	2.8		1.0	2.3
		SD	1.0		1.4	1.0
		Median	2.5		1.0	2.0

Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
		Min	2		0	0
		Max	4		2	4
		Total missing	0	4	3	22
	No				2 (50.0%)	6 (30.0%)
	Total valid response	4 (100.0%)			1 (100.0%)	4 (100.0%)
	Total missing				3	1
	Foot check	Yes	4 (100.0%)	1 (100.0%)	1 (25.0%)	14 (66.7%)
		Total valid numeric response (n)	4 (100.0%)	1 (100.0%)	1 (25.0%)	12 (57.1%)
		Mean	2.5	1.0	2.0	1.6
		SD	1.0			1.0
		Median	2.0	1.0	2.0	1.5
		Min	2	1	2	0
		Max	4	1	2	4
		Total missing	0	3	4	21
	No				3 (75.0%)	7 (33.3%)
	Total valid response	4 (100.0%)			1 (100.0%)	4 (100.0%)
	Total missing				3	1
Eye examination - Un-dilated	Yes		1 (25.0%)		3 (75.0%)	10 (45.5%)
		Total valid numeric response (n)	1 (25.0%)	0 (0.0%)	3 (75.0%)	9 (40.9%)
		Mean	1.0		122.3	41.2
		SD			210.2	121.4

Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
		Median	1.0		1.0	1.0
		Min	1		1	0
		Max	1		365	365
		Total missing	3	4	2	24
	No		3 (75.0%)	1 (100.0%)	1 (25.0%)	12 (54.5%)
	Total valid response		4 (100.0%)	1 (100.0%)	4 (100.0%)	22 (100.0%)
	Total missing			3	1	11
	Eye examination - Optical Coherence Tomography	Yes		1 (50.0%)	5 (100.0%)	11 (50.0%)
		Total valid numeric response (n)	0 (0.0%)	1 (50.0%)	4 (80.0%)	9 (40.9%)
		Mean		5.0	92.3	41.8
		SD			181.8	121.2
		Median		5.0	1.5	1.0
		Min		5	1	0
		Max		5	365	365
		Total missing	4	3	1	24
	No		3 (100.0%)	1 (50.0%)		11 (50.0%)
	Total valid response		3 (100.0%)	2 (100.0%)	5 (100.0%)	22 (100.0%)
	Total missing		1	2		11
Eye examination - Fundoscopy	Yes		2 (66.7%)	1 (50.0%)	4 (100.0%)	13 (61.9%)
		Total valid numeric	2 (66.7%)	1 (50.0%)	3 (75.0%)	11

Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
		response (n)				(52.4%)
		Mean	1.0	1.0	122.3	67.0
		SD	0.0		210.2	147.3
		Median	1.0	1.0	1.0	1.0
		Min	1	1	1	0
		Max	1	1	365	365
		Total missing	2	3	2	22
	No		1 (33.3%)	1 (50.0%)		8 (38.1%)
	Total valid response		3 (100.0%)	2 (100.0%)	4 (100.0%)	21 (100.0%)
	Total missing		1	2	1	12
Eye examination - Fluorescein Angiography	Yes		1 (25.0%)	1 (50.0%)	3 (75.0%)	13 (52.0%)
		Total valid numeric response (n)	1 (25.0%)	0 (0.0%)	2 (50.0%)	10 (40.0%)
		Mean	1.0		1.0	35.7
		SD			0.0	74.4
		Median	1.0		1.0	1.0
		Min	1		1	0
		Max	1		1	200
		Total missing	3	4	3	23
	No		3 (75.0%)	1 (50.0%)	1 (25.0%)	12 (48.0%)
	Total valid response		4 (100.0%)	2 (100.0%)	4 (100.0%)	25 (100.0%)
	Total missing			2	1	8
Eye examination -	Yes		3 (75.0%)	1 (100.0%)	2 (50.0%)	8

Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Lipid check						(42.1%)
		Total valid numeric response (n)	3 (75.0%)	1 (100.0%)	2 (50.0%)	8 (42.1%)
		Mean	1.0	1.0	1.0	1.0
		SD	0.0		0.0	0.0
		Median	1.0	1.0	1.0	1.0
		Min	1	1	1	1
		Max	1	1	1	1
		Total missing	1	3	3	25
	No		1 (25.0%)		2 (50.0%)	11 (57.9%)
	Total valid response		4 (100.0%)	1 (100.0%)	4 (100.0%)	19 (100.0%)
	Total missing			3	1	14

PT 2.10

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
In your main practice, what topics do you cover during a routine visit with a patient who has diabetes?	Diabetes management and monitoring	4 (100.0%)	1 (50.0%)	5 (100.0%)	23 (88.5%)
	Diet/nutrition	4 (100.0%)	1 (50.0%)	2 (40.0%)	13 (50.0%)
	Exercise/physical activity	4 (100.0%)	1 (50.0%)	3 (60.0%)	17 (65.4%)
	Medicines	4 (100.0%)	2 (100.0%)	4 (80.0%)	20 (76.9%)
	Foot care and inspection	4 (100.0%)	1 (50.0%)	1 (20.0%)	12 (46.2%)
	Blood pressure	4	2 (100.0%)	3 (60.0%)	17

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
		(100.0%)			(65.4%)
	Eye care and exams	4 (100.0%)	2 (100.0%)	5 (100.0%)	22 (84.6%)
	Lipid check	4 (100.0%)	2 (100.0%)	3 (60.0%)	12 (46.2%)
	Other	1 (25.0%)	0 (0.0%)	0 (0.0%)	1 (3.8%)
	Total valid response	4 (100.0%)	2 (100.0%)	5 (100.0%)	26 (100.0%)
	Total missing	0	2	0	7

PT 2.11

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Is there written information about diabetes available for patients in your main practice?	Yes, and information on eye complications is sufficient	2 (50.0%)	0 (0.0%)	5 (100.0%)	19 (76.0%)
	Yes, but information on eye complications is not sufficient	0 (0.0%)	1 (100.0%)	0 (0.0%)	2 (8.0%)
	Yes, but no information on eye complications is included	2 (50.0%)	0 (0.0%)	0 (0.0%)	2 (8.0%)
	No written information is available for patients	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (8.0%)
	Total Valid Response	4 (100.0%)	1 (100.0%)	5 (100.0%)	25 (100.0%)
	Total missing	0	3	0	8

PT 2.12

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
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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	4 (100.0%)	2 (100.0%)	5 (100.0%)	24 (92.3%)
	Don't know/Not sure	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (7.7%)
	Total Valid Response	4 (100.0%)	2 (100.0%)	5 (100.0%)	26 (100.0%)
	Total missing	0	2	0	7

PT 2.13

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Do you have written protocols/guidelines for detection and management of diabetes-related vision issue available in your main practice?	Yes, available and used by staff	2 (50.0%)	1 (50.0%)	5 (100.0%)	18 (69.2%)
	Not available	1 (25.0%)	0 (0.0%)	0 (0.0%)	1 (3.8%)
	Don't know/Not sure	1 (25.0%)	1 (50.0%)	0 (0.0%)	7 (26.9%)
	Total Valid Response	4 (100.0%)	2 (100.0%)	5 (100.0%)	26 (100.0%)
	Total missing	0	2	0	7

PT 2.14

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
What is the protocol in your main practice for timing of initial eye	After a predetermined number of years (numeric response)	0 (0.0%)	0 (0.0%)	1 (20.0%)	2 (8.0%)

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
exams for persons with diabetes - Type I?	(n)				
	Mean			5.0	5.0
	SD				0.0
	Median			5.0	5.0
	Min			5	5
	Max			5	5
	After a predetermined age (numeric response) (n)	0 (0.0%)	1 (50.0%)	1 (20.0%)	3 (12.0%)
	Mean			10.0	10.0
	SD				0.0
	Median			10.0	10.0
	Min			10	10
	Max			10	10
	As soon as they are diagnosed	2 (50.0%)			13 (52.0%)
	No standard practice, timing varies case by case	1 (25.0%)			1 (4.0%)
	Don't know/Not sure				1 (4.0%)
	Other	1 (25.0%)	1 (50.0%)	1 (20.0%)	5 (20.0%)
	Total valid response	4 (100.0%)	2 (100.0%)	5 (100.0%)	25 (100.0%)
	Total missing		2		8
What is the protocol in your main practice for timing of initial eye exams for persons with diabetes - Type II?	After a predetermined number of years (numeric response) (n)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	Mean				
	SD				

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Median				
	Min				
	Max				
	After a predetermined age (numeric response) (n)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	Mean				
	SD				
	Median				
	Min				
	Max				
	As soon as they are diagnosed	4 (100.0%)	2 (100.0%)	5 (100.0%)	24 (92.3%)
	Don't know/Not sure				1 (3.8%)
	Other				1 (3.8%)
	Total valid response	4 (100.0%)	2 (100.0%)	5 (100.0%)	26 (100.0%)
	Total missing		2		7

PT 2.15

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
What is the protocol in your main practice for timing of follow-up eye examinations for persons with diabetes?	Once a year	2 (50.0%)	0 (0.0%)	1 (20.0%)	4 (15.4%)
	Every two years	0 (0.0%)	1 (50.0%)	0 (0.0%)	5 (19.2%)
	More than every two years	0 (0.0%)	0 (0.0%)	1 (20.0%)	1 (3.8%)
	Other	2 (50.0%)	1 (50.0%)	3 (60.0%)	14 (53.8%)

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Don't know/Not sure	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (7.7%)
	Total Valid Response	4 (100.0%)	2 (100.0%)	5 (100.0%)	26 (100.0%)
	Total missing	0	2	0	7

PT 2.16

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Do you screen patients for DR?	Yes	2 (50.0%)	1 (33.3%)	5 (100.0%)	19 (70.4%)
	No	2 (50.0%)	2 (66.7%)		8 (29.6%)
	Total valid response	4 (100.0%)	3 (100.0%)	5 (100.0%)	27 (100.0%)
	Total missing		1		6
Where do you screen patients?	In clinic	1 (50.0%)	1 (100.0%)	5 (100.0%)	14 (73.7%)
	Outreach	1 (50.0%)			5 (26.3%)
	Other				4 (21.1%)
	Total valid response	2 (100.0%)	1 (100.0%)	5 (100.0%)	19 (100.0%)
	Total missing	2	3		14

PT 2.17

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
What patient characteristics influence your vision care and/or vision referrals?	Diabetes duration	1 (25.0%)	0 (0.0%)	4 (80.0%)	14 (56.0%)
	Patient's age	1 (25.0%)	0 (0.0%)	2 (40.0%)	7 (28.0%)
	Patient's gender	0 (0.0%)	0 (0.0%)	1 (20.0%)	1 (4.0%)

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Presence of comorbidities such as hypertension, etc.	1 (25.0%)	0 (0.0%)	4 (80.0%)	11 (44.0%)
	High glucose levels	1 (25.0%)	0 (0.0%)	4 (80.0%)	14 (56.0%)
	Patient adherence to recommendations	0 (0.0%)	0 (0.0%)	1 (20.0%)	1 (4.0%)
	None of the above	1 (25.0%)	0 (0.0%)	1 (20.0%)	4 (16.0%)
	Not applicable	2 (50.0%)	1 (100.0%)	0 (0.0%)	7 (28.0%)
	Total valid response	4 (100.0%)	1 (100.0%)	5 (100.0%)	25 (100.0%)
	Total missing	0	3	0	8

PT 2.18

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
What are the major barriers to optimizing eye health faced by patients with diabetes in your main practice?	Cost of care	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (4.0%)
	Proximity to care	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (8.0%)
	Long wait time for appointment	0 (0.0%)	0 (0.0%)	1 (25.0%)	4 (16.0%)
	Long wait time on the day of visit	1 (25.0%)	1 (50.0%)	1 (25.0%)	3 (12.0%)
	Lack of knowledge and/or awareness	0 (0.0%)	1 (50.0%)	0 (0.0%)	6 (24.0%)
	Patients fear of treatment/results	0 (0.0%)	0 (0.0%)	0 (0.0%)	5 (20.0%)
	Limited access to diabetes specialists	0 (0.0%)	0 (0.0%)	1 (25.0%)	2 (8.0%)
	Limited access to eye specialists	0 (0.0%)	0 (0.0%)	4 (100.0%)	12 (48.0%)

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Patients feel eye complications are unlikely	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (8.0%)
	Patients feel eye exams are not important	0 (0.0%)	1 (50.0%)	0 (0.0%)	9 (36.0%)
	Patients have competing responsibilities and priorities	1 (25.0%)	0 (0.0%)	1 (25.0%)	7 (28.0%)
	Clinic too small or lack necessary equipment/staff	0 (0.0%)	0 (0.0%)	2 (50.0%)	2 (8.0%)
	Other	3 (75.0%)	1 (50.0%)	1 (25.0%)	9 (36.0%)
	Total valid response	4 (100.0%)	2 (100.0%)	4 (100.0%)	25 (100.0%)
	Total missing	0	2	1	8

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	4 (100.0%)	1 (50.0%)	5 (100.0%)	23 (88.5%)
	No	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (7.7%)
	Don't know/Not sure	0 (0.0%)	1 (50.0%)	0 (0.0%)	1 (3.8%)
	Total Valid Response	4 (100.0%)	2 (100.0%)	5 (100.0%)	26 (100.0%)
	Total missing	0	2	0	7

PT 2.20

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Do you share relevant patient information with other health care professionals involved in the patients care e.g. his or her general practitioner, ophthalmologist, podiatrist?	Yes	2 (50.0%)	1 (50.0%)	5 (100.0%)	20 (76.9%)
	No	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (3.8%)
	Don't know/Not sure	2 (50.0%)	1 (50.0%)	0 (0.0%)	5 (19.2%)
	Total Valid Response	4 (100.0%)	2 (100.0%)	5 (100.0%)	26 (100.0%)
	Total missing	0	2	0	7

PT 3.1

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Please indicate your age:	30 - 39		1 (50.0%)	1 (20.0%)	2 (7.7%)
	40 - 49			2 (40.0%)	7 (26.9%)
	50 - 59			2 (40.0%)	11 (42.3%)
	60 - 69				6 (23.1%)
	Total valid response		2 (100.0%)	5 (100.0%)	26 (100.0%)
	Total missing		2		7
What is your gender?	Female	3 (75.0%)	1 (100.0%)	2 (40.0%)	20 (80.0%)
	Male	1 (25.0%)		3 (60.0%)	5 (20.0%)
	Total valid response	4 (100.0%)	1 (100.0%)	5 (100.0%)	25 (100.0%)
	Total missing		3		8
What is your highest level of	College/University	2 (50.0%)	1 (50.0%)	2 (50.0%)	20 (80.0%)

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
education completed?					
	Graduate or advanced degree (e.g. PhD, MD, etc)	2 (50.0%)	1 (50.0%)	2 (50.0%)	5 (20.0%)
	Total valid response	4 (100.0%)	2 (100.0%)	4 (100.0%)	25 (100.0%)
	Total missing		2	1	8

PT 4.1

Question	Response	Ophthalmologist
What percentage of your patients have diabetic retinopathy	Total valid numeric response (n)	4
	Mean	18.8
	SD	17.0
	Median	15.0
	Min	5
	Max	40
	Total missing	1

PT 4.2

Question	Response	Ophthalmologist
What percentage of your patients have diabetic macular edema?	Total valid numeric response (n)	4
	Mean	8.0
	SD	8.1
	Median	8.0
	Min	1
	Max	15
	Total missing	1

PT 4.3

Question	Response	Ophthalmologist
What is the average amount of time your patients wait for an appointment to be screened for diabetic eye	More than 2 months but less than 3	2 (50.0%)

Question	Response	Ophthalmologist
disease in your practice?	months	
	Six or more months	2 (50.0%)
	Total Valid Response	4 (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	2 (50.0%)
	More than 1 week but less than 1 month	1 (25.0%)
	More than 1 month but less than 2 months	1 (25.0%)
	Total Valid Response	4 (100.0%)
	Total missing	1

PT 4.5

Type of Treatment	Question	Response/time	Ophthalmologist
Laser photocoagulation	Is the treatment available?	Available in practice	4 (100.0%)
		Total valid response	4 (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)	3 (100.0%)
		Mean	3.0
		SD	1.7
		Median	4.0
		Min	1
		Max	4
		Total valid response	3 (100.0%)
		Total missing	2
	What is the average amount of time your patients wait for a first treatment?(weeks)	Total valid numeric response (n)	3 (100.0%)

Type of Treatment	Question	Response/time	Ophthalmologist
	What is the average amount of time your patients wait for a second treatment?(weeks)	Mean	3.3
		SD	1.2
		Median	4.0
		Min	2
		Max	4
		Total valid response	3 (100.0%)
		Total missing	2
		Total valid numeric response (n)	4 (100.0%)
		Mean	4.5
		SD	2.5
		Median	4.0
		Min	2
		Max	8
		Total valid response	4 (100.0%)
		Total missing	1
Anti-VEGF therapies	Is the treatment available?	Available locally	2 (50.0%)
	What is the average amount of time your patients wait for a consultation appointment? (weeks)	Available in practice	2 (50.0%)
		Total valid response	4 (100.0%)
		Total missing	1
		Total valid numeric response (n)	4 (100.0%)
		Mean	1.5
		SD	0.6
		Median	1.5
		Min	1
		Max	2
		Total valid response	4 (100.0%)
		Total missing	1

Type of Treatment	Question	Response/time	Ophthalmologist
	What is the average amount of time your patients wait for a first treatment?(weeks)	Total valid numeric response (n)	4 (100.0%)
		Mean	2.3
		SD	1.3
		Median	2.0
		Min	1
		Max	4
		Total valid response	4 (100.0%)
		Total missing	1
	What is the average amount of time your patients wait for a second treatment?(weeks)	Total valid numeric response (n)	4 (100.0%)
		Mean	2.8
		SD	3.6
		Median	1.5
		Min	0
		Max	8
		Total valid response	4 (100.0%)
		Total missing	1
Intravitreal steroid	Is the treatment available?	Available locally	2 (50.0%)
		Available in practice	2 (50.0%)
		Total valid response	4 (100.0%)
		Total missing	1
	What is the average amount of time your patients wait for a consultation appointment? (weeks)	Total valid numeric response (n)	4 (100.0%)
		Mean	1.5
		SD	0.6
		Median	1.5
		Min	1
		Max	2
		Total valid	4 (100.0%)

Type of Treatment	Question	Response/time	Ophthalmologist
	What is the average amount of time your patients wait for a first treatment?(weeks)	response	
		Total missing	1
		Total valid numeric response (n)	4 (100.0%)
		Mean	1.8
		SD	0.5
		Median	2.0
		Min	1
		Max	2
		Total valid response	4 (100.0%)
		Total missing	1
	What is the average amount of time your patients wait for a second treatment?(weeks)	Total valid numeric response (n)	4 (100.0%)
		Mean	7.0
		SD	6.6
		Median	5.0
		Min	2
		Max	16
		Total valid response	4 (100.0%)
		Total missing	1
Uncomplicated vitrectomy	Is the treatment available?	Available locally	3 (75.0%)
	What is the average amount of time your patients wait for a consultation appointment? (weeks)	Available in practice	1 (25.0%)
		Total valid response	4 (100.0%)
		Total missing	1
		Total valid numeric response (n)	3 (100.0%)
		Mean	6.3
		SD	5.5
		Median	6.0

Type of Treatment	Question	Response/time	Ophthalmologist
		Min	1
		Max	12
		Total valid response	3 (100.0%)
		Total missing	2
	What is the average amount of time your patients wait for a first treatment?(weeks)	Total valid numeric response (n)	3 (100.0%)
		Mean	6.7
		SD	4.6
		Median	4.0
		Min	4
		Max	12
		Total valid response	3 (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 (33.3%)
		Mean	12.0
		SD	
		Median	12.0
		Min	12
		Max	12
		Don't know/not sure	2 (66.7%)
		Total valid response	3 (100.0%)
		Total missing	2
Complex vitreo-retinal surgery	Is the treatment available?	Available within country	1 (25.0%)
		Available locally	2 (50.0%)
		Available in practice	1 (25.0%)
		Total valid response	4 (100.0%)
		Total missing	1

Type of Treatment	Question	Response/time	Ophthalmologist
	What is the average amount of time your patients wait for a consultation appointment? (weeks)	Total valid numeric response (n)	4 (100.0%)
		Mean	6.8
		SD	4.6
		Median	7.0
		Min	1
		Max	12
		Total valid response	4 (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)	3 (100.0%)
		Mean	6.7
		SD	4.6
		Median	4.0
		Min	4
		Max	12
		Total valid response	3 (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 (33.3%)
		Mean	12.0
		SD	
		Median	12.0
		Min	12
		Max	12
		Don't know/not sure	2 (66.7%)
		Total valid response	3 (100.0%)
		Total missing	2

Question	Response	Ophthalmologist
Do you personally administer treatment for diabetic retinopathy?	Yes	3 (75.0%)
	No	1 (25.0%)
	Total valid response	4 (100.0%)
	Total missing	1
Who administer it?	Another provider in your practice	1 (100.0%)
	Total valid response	1 (100.0%)
	Total missing	4

PT 4.7

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.	3 (100.0%)
	High glucose levels	2 (66.7%)
	Patient adherence to recommendations	2 (66.7%)
	Total valid response	3 (100.0%)
	Total missing	2

PT 4.8

Question	Response	Ophthalmologist
Do you treat diabetic retinopathy and diabetic macular edema based on:	Visual outcome	1 (25.0%)
	Anatomical outcomes	1 (25.0%)
	Both	2 (50.0%)
	Total Valid Response	4 (100.0%)
	Total missing	1

PT 4.9

Question	Response	Ophthalmologist
How are your patients with diabetes screened for diabetic eye disease?	Fundoscopy undilated	1 (25.0%)
	Fundoscopy dilated	3 (75.0%)
	Retinal photo	4 (100.0%)
	Optical Coherence Tomography	3 (75.0%)
	Fluorescein Angiography	2 (50.0%)
	Total valid response	4 (100.0%)
	Total missing	1

PT 4.10

Question	Response	Ophthalmologist
In your opinion, do the majority of your patients present:	In time for screening	4 (100.0%)
	Total Valid Response	4 (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%)
	Total missing	1
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	2

PT 4.12

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

Question	Response	Ophthalmologist
	Response	
	Total missing	4

PT 4.13

Question	Response	Ophthalmologist
How is outreach for screening for diabetic eye disease done in your main practice?	Health fairs for people with diabetes	1 (25.0%)
	Mobile screening centers	1 (25.0%)
	Other	2 (50.0%)
	Not done	1 (25.0%)
	Total valid response	4 (100.0%)
	Total missing	1

PT 4.14

Question	Response	Ophthalmologist
What do you perceive to be the greatest challenges for improving patient outcomes in diabetic eye disease?	Late diagnosis	1 (33.3%)
	Referral pathways	2 (66.7%)
	No universal guidelines on referral/screening	1 (33.3%)
	No universal guidelines on how to treat	1 (33.3%)
	No universal guideline on when to treat	1 (33.3%)
	Other	1 (33.3%)
	Total valid response	3 (100.0%)
	Total missing	2

EXP 1

Question	Response	Without DED (%)	With DED (%)	With DME (%)
Which of the following complications of diabetes do you have?	Irritable bowel disease	2 (3.1%)	1 (25.0%)	1 (16.7%)
	Loss of feeling in hands or toes (neuropathy)	15 (23.4%)	3 (75.0%)	4 (66.7%)

Question	Response	Without DED (%)	With DED (%)	With DME (%)
	Vision loss	5 (7.8%)	1 (25.0%)	3 (50.0%)
	Cardiovascular disease/Stroke	6 (9.4%)	0 (0.0%)	2 (33.3%)
	Kidney disease	1 (1.6%)	0 (0.0%)	1 (16.7%)
	Broken bones or fractures	2 (3.1%)	1 (25.0%)	0 (0.0%)
	Foot ulcers	3 (4.7%)	0 (0.0%)	0 (0.0%)
	Amputation	0 (0.0%)	1 (25.0%)	0 (0.0%)
	None	34 (53.1%)	0 (0.0%)	0 (0.0%)
	Don't know/Not sure	5 (7.8%)	0 (0.0%)	1 (16.7%)
	Total Valid Response	64 (100.0%)	4 (100.0%)	6 (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".

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	25 (41.0%)	2 (50.0%)	5 (100.0%)
Impairment or health problem			
Diabetes	19 (70.4%)	2 (100.0%)	2 (40.0%)
Back or neck problem	17 (58.6%)	1 (100.0%)	1 (20.0%)
Hypertension/high blood pressure	12 (46.2%)	0 (0.0%)	2 (40.0%)
Arthritis/rheumatism	11 (40.7%)	0 (0.0%)	0 (0.0%)
Hearing problem	10 (40.0%)	0 (0.0%)	4 (80.0%)
Eye/vision problem	10 (38.5%)	1 (50.0%)	2 (40.0%)
Walking problem	8 (33.3%)	0 (0.0%)	1 (20.0%)
Lung/breathing problem	5 (20.8%)	0 (0.0%)	3 (60.0%)
Fractures, bone/joint injury	4 (16.7%)	0 (0.0%)	0 (0.0%)
Mental or emotional health	3 (11.5%)	2 (100.0%)	2 (40.0%)
Heart problem	3 (12.0%)	0 (0.0%)	2 (40.0%)
Cancer	2 (7.7%)	0 (0.0%)	1 (20.0%)
Stroke problem	1 (4.0%)	0 (0.0%)	2 (40.0%)

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	40 (65.6%)	1 (25.0%)	4 (80.0%)
Self-rated health: Poor	21 (34.4%)	3 (75.0%)	1 (20.0%)
Physically unhealthy days	17 (38.6%)	0 (0.0%)	1 (50.0%)
Mentally unhealthy days	9 (18.8%)	1 (33.3%)	0 (0.0%)
Unhealthy days	21 (50.0%)	1 (33.3%)	1 (50.0%)
Activity limitation days	16 (50.0%)	0 (0.0%)	1 (100.0%)

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

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

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

EXP 4

Item	Response	All respondents	Respondents with Type I diabetes	Respondents with Type II diabetes
How do you manage your diabetes?	Diet	20 (26.0%)	3 (17.6%)	16 (27.6%)
	Oral medicine	47 (61.0%)	1 (5.9%)	46 (79.3%)
	Exercise	37 (48.1%)	6 (35.3%)	30 (51.7%)
	Insulin	40 (51.9%)	17 (100.0%)	22 (37.9%)

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

EXP 5.1

Item	Response	Without DED (%)	With DED (%)	With DME (%)
Are you currently working?	Working for pay	15 (24.6%)	1 (25.0%)	0 (0.0%)
	Working without pay at home (e.g. housework, farming)	0 (0.0%)	0 (0.0%)	2 (40.0%)
	Volunteering	1 (1.6%)	1 (25.0%)	2 (40.0%)
	Retired	40 (65.6%)	1 (25.0%)	1 (20.0%)
	Student	1 (1.6%)	0 (0.0%)	0 (0.0%)
	Not working	4 (6.6%)	1 (25.0%)	0 (0.0%)
	Total Valid Response	61 (100.0%)	4 (100.0%)	5 (100.0%)

Item	Response	Without DED (%)	With DED (%)	With DME (%)
	Total missing	8	0	1
Do you receive assistance from the government?	Income assistance	1 (1.7%)	0 (0.0%)	0 (0.0%)
	Medical assistance	7 (11.9%)	0 (0.0%)	3 (60.0%)
	Food assistance	0 (0.0%)	1 (25.0%)	1 (20.0%)
	Housing assistance	2 (3.4%)	1 (25.0%)	1 (20.0%)
	Pension assistance	6 (10.2%)	1 (25.0%)	0 (0.0%)
	None of the above	44 (74.6%)	1 (25.0%)	1 (20.0%)
	Total valid response	59 (100.0%)	4 (100.0%)	5 (100.0%)
	Total missing	10	0	1
Did you have trouble paying for food at anytime during the past year?	Yes	1 (1.6%)	1 (25.0%)	4 (80.0%)
	No	61 (98.4%)	3 (75.0%)	1 (20.0%)
	Total Valid Response	62 (100.0%)	4 (100.0%)	5 (100.0%)
	Total missing	7	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	2 (40.0%)	0 (0.0%)	0 (0.0%)
	Working without pay at home (e.g. housework, farming)	0 (0.0%)	0 (0.0%)	1 (100.0%)
	Volunteering	0 (0.0%)	1 (50.0%)	0 (0.0%)
	Student	1 (20.0%)	0 (0.0%)	0 (0.0%)
	Not working	2 (40.0%)	1 (50.0%)	0 (0.0%)
	Total Valid Response	5 (100.0%)	2 (100.0%)	1 (100.0%)
	Total missing	1	0	0
Do you receive assistance from the government?	Income assistance	1 (20.0%)	0 (0.0%)	0 (0.0%)

Item	Response	Without DED (%)	With DED (%)	With DME (%)
	Medical assistance	0 (0.0%)	0 (0.0%)	1 (100.0%)
	Food assistance	0 (0.0%)	1 (50.0%)	0 (0.0%)
	Housing assistance	1 (20.0%)	1 (50.0%)	0 (0.0%)
	None of the above	4 (80.0%)	0 (0.0%)	0 (0.0%)
	Total valid response	5 (100.0%)	2 (100.0%)	1 (100.0%)
	Total missing	1	0	0
Did you have trouble paying for food at anytime during the past year?	Yes	0 (0.0%)	1 (50.0%)	1 (100.0%)
	No	5 (100.0%)	1 (50.0%)	0 (0.0%)
	Total Valid Response	5 (100.0%)	2 (100.0%)	1 (100.0%)
	Total missing	1	0	0

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

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

NB [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	8 (100.0%)	1 (100.0%)	0 (0.0%)
	Working without pay at home (e.g. housework, farming)	0 (0.0%)	0 (0.0%)	1 (33.3%)
	Volunteering	0 (0.0%)	0 (0.0%)	2 (66.7%)
	Total Valid Response	8 (100.0%)	1 (100.0%)	3 (100.0%)
	Total missing	0	0	1
Do you receive assistance from the government?	Medical assistance	2 (25.0%)	0 (0.0%)	2 (66.7%)
	Food assistance	0 (0.0%)	0 (0.0%)	1 (33.3%)
	Housing assistance	0 (0.0%)	0 (0.0%)	1 (33.3%)
	Pension assistance	0 (0.0%)	1 (100.0%)	0 (0.0%)
	None of the above	6 (75.0%)	0 (0.0%)	0 (0.0%)

Item	Response	Without DED (%)	With DED (%)	With DME (%)
	Total valid response	8 (100.0%)	1 (100.0%)	3 (100.0%)
	Total missing	0	0	1
Did you have trouble paying for food at anytime during the past year?	Yes	0 (0.0%)	0 (0.0%)	3 (100.0%)
	No	8 (100.0%)	1 (100.0%)	0 (0.0%)
	Total Valid Response	8 (100.0%)	1 (100.0%)	3 (100.0%)
	Total missing	0	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	5 (11.1%)	0 (0.0%)	0 (0.0%)
	Volunteering	1 (2.2%)	0 (0.0%)	0 (0.0%)
	Retired	37 (82.2%)	1 (100.0%)	1 (100.0%)
	Not working	2 (4.4%)	0 (0.0%)	0 (0.0%)
	Total Valid Response	45 (100.0%)	1 (100.0%)	1 (100.0%)
	Total missing	7	0	0
Do you receive assistance from the government?	Medical assistance	5 (11.6%)	0 (0.0%)	0 (0.0%)
	Housing assistance	1 (2.3%)	0 (0.0%)	0 (0.0%)
	Pension assistance	5 (11.6%)	0 (0.0%)	0 (0.0%)
	None of the above	32 (74.4%)	1 (100.0%)	1 (100.0%)
	Total valid response	43 (100.0%)	1 (100.0%)	1 (100.0%)
	Total missing	9	0	0
Did you have trouble paying for food at anytime during the past year?	Yes	1 (2.2%)	0 (0.0%)	0 (0.0%)
	No	45 (97.8%)	1 (100.0%)	1 (100.0%)

Item	Response	Without DED (%)	With DED (%)	With DME (%)
	Total Valid Response	46 (100.0%)	1 (100.0%)	1 (100.0%)
	Total missing	6	0	0

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

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

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

EXP 5.5: Age group 80+ years

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

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

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

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

EXP 6

Group	Subgroup	All respondents	Type 1 diabetes	Type 2 diabetes	With DED (%)	With DME (%)
All respondents		79 (100%)	17 (21.5%)	60 (75.9%)	4 (5.1%)	6 (7.6%)
Gender	Male	36 (50.0%)	6 (16.7%)	29 (80.6%)	1 (2.8%)	0 (0.0%)
	Female	36 (50.0%)	11 (30.6%)	24 (66.7%)	3 (8.3%)	5 (13.9%)
	Total Missing	7	0	7	0	1
Age	18-39 yrs	9 (11.4%)	7 (77.8%)	2 (22.2%)	2 (22.2%)	1 (11.1%)
	40-59 yrs	13 (16.5%)	4 (30.8%)	9 (69.2%)	1 (7.7%)	4 (30.8%)
	60-79 yrs	54 (68.4%)	5 (9.3%)	47 (87.0%)	1 (1.9%)	1 (1.9%)

Group	Subgroup	All respondents	Type 1 diabetes	Type 2 diabetes	With DED (%)	With DME (%)
	80 yrs and over	3 (3.8%)	1 (33.3%)	2 (66.7%)	0 (0.0%)	0 (0.0%)
Time since diagnosis	Within the last year	4 (5.2%)	1 (25.0%)	3 (75.0%)	0 (0.0%)	1 (25.0%)
	1 - 5 years ago	16 (20.8%)	3 (18.8%)	13 (81.3%)	1 (6.3%)	2 (12.5%)
	6 - 10 years ago	18 (23.4%)	3 (16.7%)	14 (77.8%)	0 (0.0%)	1 (5.6%)
	11 - 15 years ago	17 (22.1%)	2 (11.8%)	15 (88.2%)	1 (5.9%)	0 (0.0%)
	16 - 20 years ago	7 (9.1%)	0 (0.0%)	7 (100.0%)	0 (0.0%)	0 (0.0%)
	21 years ago or longer	13 (16.9%)	8 (61.5%)	4 (30.8%)	2 (15.4%)	1 (7.7%)
	Don't know/Not sure	2 (2.6%)	0 (0.0%)	2 (100.0%)	0 (0.0%)	1 (50.0%)
	Total Missing	2	0	2	0	0
Control of Diabetes	Controlled	63 (81.8%)	15 (23.8%)	46 (73.0%)	3 (4.8%)	3 (4.8%)
	Not controlled	12 (15.6%)	2 (16.7%)	10 (83.3%)	1 (8.3%)	2 (16.7%)
	Don't know/Not sure	2 (2.6%)	0 (0.0%)	2 (100.0%)	0 (0.0%)	1 (50.0%)
	Total Missing	2	0	2	0	0

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

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

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

EXP 7

Question	Response	With DED n (%)	With DME n (%)
Have you had any treatment for diabetic eye disease?	Yes	3 (75.0%)	6 (100.0%)
	No	1 (25.0%)	0 (0.0%)
	Total valid response	4 (100.0%)	6 (100.0%)
What treatment did you receive?	Laser	2 (66.7%)	1 (16.7%)
	Anti-VEGF	0 (0.0%)	5 (83.3%)
	Surgery	1 (33.3%)	1 (16.7%)

Question	Response	With DED n (%)	With DME n (%)
	Total valid response	3 (100.0%)	6 (100.0%)
	Total missing	1	0
Did you complete the treatment?	Yes	2 (66.7%)	2 (33.3%)
	No	0 (0.0%)	3 (50.0%)
	Still receiving treatment	1 (33.3%)	1 (16.7%)
	Total valid response	3 (100.0%)	6 (100.0%)
	Total missing	1	0
Do you feel that the treatment worked?	Yes, but vision stayed the same	1 (33.3%)	3 (100.0%)
	No	1 (33.3%)	0 (0.0%)
	Don't know/Not sure	1 (33.3%)	0 (0.0%)
	Total valid response	3 (100.0%)	3 (100.0%)
	Total missing	1	3
What is/are the reason(s) that you did not complete the treatment?	Did not like the treatment	0 (0.0%)	1 (33.3%)
	Treatment was too expensive	0 (0.0%)	1 (33.3%)
	Eye doctor was located too far away	0 (0.0%)	2 (66.7%)
	Appointment times were not convenient	0 (0.0%)	1 (33.3%)
	Too much burden on my family/friends	0 (0.0%)	1 (33.3%)
	Total valid response	0 (0.0%)	3 (100.0%)
	Total missing	4	3
What are the reason(s) that you have not had treatment for diabetic eye disease?	My doctor did not recommend any treatment	1 (100.0%)	0 (0.0%)
	Total valid response	1 (100.0%)	0 (0.0%)
	Total missing	3	6

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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