

The Diabetic Retinopathy Barometer Report

South Africa



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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), and the findings from South Africa are reported here.

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

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

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

Goal

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

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

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

Background

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

Phase II was a multi-country quantitative study conducted in 41 countries to investigate the current level of awareness of the risk of DR and of the need for prevention, screening and management to prevent vision loss. The study also sought to better understand the nature of health services and supports available, related national and international policies and the social and economic burden of the disease.

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

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

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

Study Populations

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

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

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

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

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

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

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

Introduction

South Africa Study

Demographic Characteristics

South Africa is estimated to be the fifth most populous country in Africa with a population of approximately 54.3 million inhabitants¹.

According to most recent statistics, it is estimated that 29% of the population is under the age of 15 years and 5.1% over the age of 65. It is important to note that the life expectancy in South Africa is currently ~57 years of age².

By 2050, the population distribution in South Africa is expected to increase by 33%. However, there will be a decrease in the percentage of those 15 and younger (21%) and a drastic increase of 165% for those aged 65 years or older. In just over 30 years the population of 65 years or older will reach an all-time high of approximately 7.5 million, ~10% of the population with an increase in life expectancy to ~69 years of age.

Diabetes Profile³

There are 415 million people with diabetes in the world and approximately 14.2 million people in Africa. By 2040, this number is anticipated to rise to 34.2 million.

Forty-nine diverse sub-Saharan countries and territories comprise the African region, from Western Sahara to South Africa and from the Island of Reunion to the archipelago of Cape Verde. Some of the world's highest rates of economic growth have recently occurred in African countries such as Ethiopia, Liberia, and the Democratic Republic of Congo.

The African region has the highest proportion of estimated undiagnosed diabetes (66.7%), which accounts to ~9.5 million people living in this region whom are unaware that they may have diabetes. Of the 14.2 million living with diabetes, over half (58.8%) live in cities, even though the population in the region is predominantly (61.3%) rural.

While the African region has the lowest age-adjusted comparative diabetes prevalence rate of any IDF regions, there are still many countries with relatively high diabetes prevalence rates. South Africa has the highest number of people living with diabetes in the region at ~2.3 million (1,163.7-4,620.6±), which accounts to ~16% of people living with diabetes in this region.

South Africa's national prevalence (20-79 years) is 7% (3.6-14.1±) and the diabetes age-adjusted comparative prevalence is 7.6% (3.9-14.7±). Deaths attributed to diabetes in South Africa in 2015 were 57,318, which accounts to ~18% of the diabetes related deaths experienced in this region. The estimated number of undiagnosed cases in 2015 was ~1.4 million (603.0-2,394.4±).

Study Populations: South Africa

As reported by 70 respondents with diabetes in South Africa, 11% were diagnosed with DED and no one was diagnosed with DME.

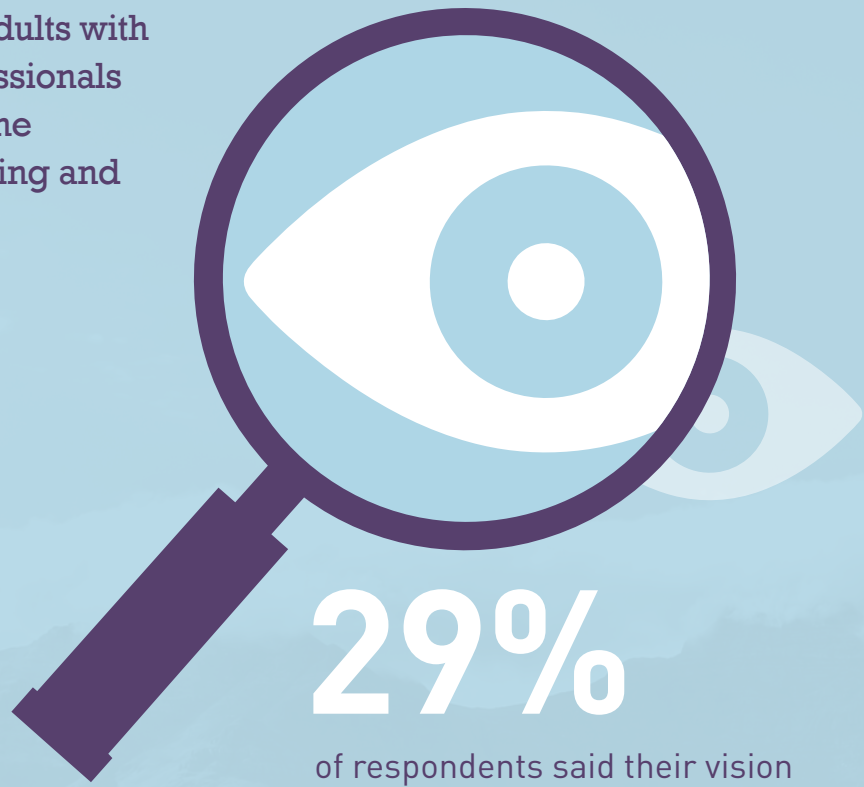
Sixty-eight health care professionals completed the survey in South Africa. Of these, nine were diabetes specialist providers (13%), 17 were ophthalmologists (25%), and five were primary care providers (7.4%). The remaining respondents were either optometrists, nurses, health educators or other types of professionals.

The DR Barometer Study: South Africa Overview

The DR Barometer study was conducted in 41 countries. In South Africa, 70 adults with diabetes and 68 health care professionals provided new information about the experiences of living with, managing and treating diabetes, DR and DME.

47%

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

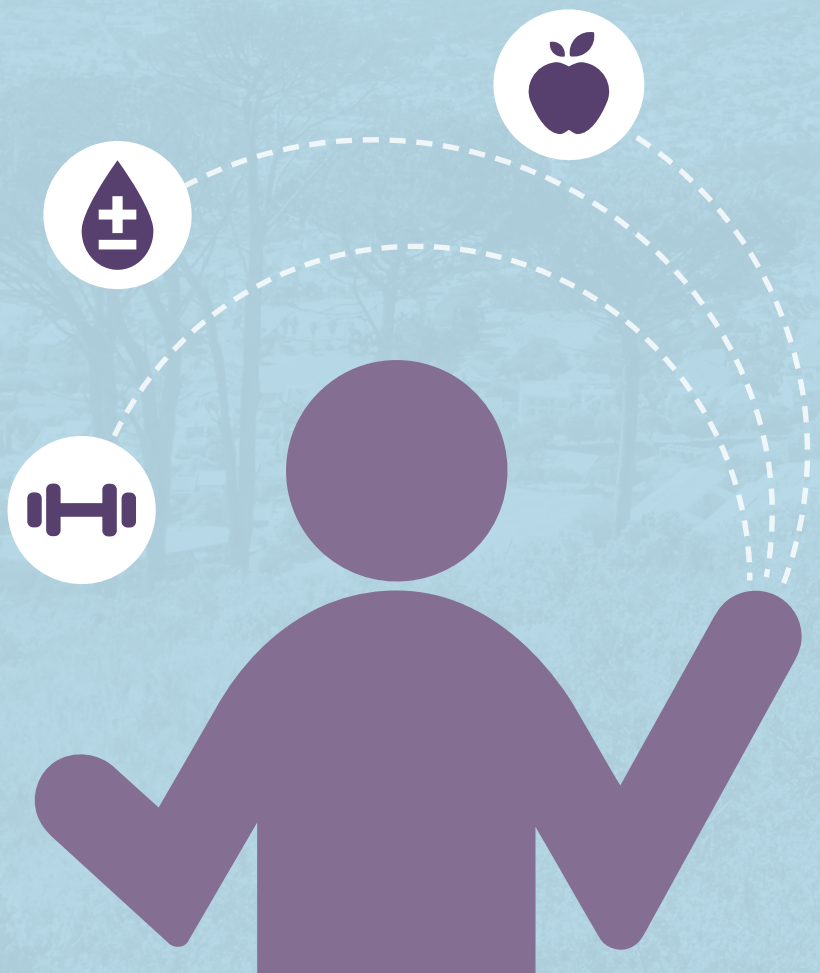


29%

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

50%

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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86%



of patients with vision loss due to DR or DME said that their condition made everyday activities, **such as driving**, working and completing basic household tasks difficult and in some cases impossible

36%

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



25%

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



South Africa

DR Barometer Findings:

Adults with Diabetes

Key Demographic Characteristics

Seventy adults with diabetes completed the patients' survey in South Africa: 82% were female and 18% were male. Eighty percent lived in an urban setting and 20% in a non-urban setting (see Appendix Table 4.2).

The education levels of all respondents were as follows: 2.1% of respondents were educated to a primary school level, 40% to a secondary school level, 21% to a college or university level, and 36% to a graduate or post-graduate level (see Appendix Table 4.3).

Fifty-three percent of all respondents were in paid employment, 26% were retired, and 7.5% were not working (see Appendix Table 4.4).

Most respondents (37%) were aged between 60 and 79 years (29% were 18-39 years, 33% were 40-59 years and 1.4% were 80 years or older). Sixty-two percent were of traditional working age (18- 59 years) (see Table 1).

Of the respondents in South Africa, 33% had been diagnosed with type 1 diabetes and 50% with type 2 diabetes. A further 17% of respondents were either unsure of or did not know their type of diabetes (see Appendix Table 2.1).

Eleven percent of respondents (n=8) had been diagnosed with DED.

Three percent of those surveyed were diagnosed with diabetes within the last year, 1 - 5 years ago (29%), 6 - 10 years ago (20%), 11 - 15 years ago (17%), 16 - 20 years ago (7.7%), and 21 years ago or more (19%) (see Appendix Table 2.2).

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

Amongst 18 to 39-year-olds, 70% had type 1 and 15% had type 2 diabetes. In the 40-59 age group, 22% had type 1 and 74% had type 2 diabetes, 15% of 60-79-year-olds had type 1 diabetes and 54% had type 2.

In people aged 18-39 years 10% had DED, this increased to 23% in those aged 60-79 years. Forty-two percent of respondents diagnosed more than 21 years ago had DED.

While most (78%) respondents reported that their diabetes was well controlled, there were almost one in five (19%) who felt that this was not the case.

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		70 (100.0%)	23 (32.9%)	35 (50.0%)	8 (11.4%)	40 (13.8%)
Gender	Male	9 (18.0%)	5 (55.6%)	4 (44.4%)	2 (22.2%)	22 (18.2%)
	Female	41 (82.0%)	10 (24.4%)	21 (51.2%)	5 (12.2%)	18 (14.1%)
	Total Missing	20	8	10	1	0
Age	18-39 yrs.	20 (28.6%)	14 (70.0%)	3 (15.0%)	2 (10.0%)	4 (5.8%)
	40-59 yrs.	23 (32.9%)	5 (21.7%)	17 (73.9%)	0 (0.0%)	11 (10.6%)
	60-79 yrs.	26 (37.1%)	4 (15.4%)	14 (53.8%)	6 (23.1%)	21 (19.6%)
	80 yrs. plus	1 (1.4%)	0 (0.0%)	1 (100.0%)	0 (0.0%)	4 (40.0%)
Time since diagnosis	Within the last year	2 (3.1%)	0 (0.0%)	1 (50.0%)	0 (0.0%)	0 (0.0%)
	1 - 5 yrs.	19 (29.2%)	3 (15.8%)	11 (57.9%)	0 (0.0%)	3 (6.8%)
	6 - 10 yrs.	13 (20.0%)	4 (30.8%)	9 (69.2%)	0 (0.0%)	2 (6.3%)
	11 - 15 yrs.	11 (16.9%)	2 (18.2%)	5 (45.5%)	2 (18.2%)	3 (8.1%)
	16 - 20 yrs.	5 (7.7%)	1 (20.0%)	3 (60.0%)	1 (20.0%)	2 (8.7%)
	21 yrs. plus	12 (18.5%)	11 (91.7%)	1 (8.3%)	5 (41.7%)	30 (22.7%)
	Don't know/ Not sure	3 (4.6%)	0 (0.0%)	2 (66.7%)	0 (0.0%)	0 (0.0%)
	Total Missing	5	2	3	0	0
Control of Diabetes	Controlled	46 (78.0%)	13 (28.3%)	24 (52.2%)	8 (17.4%)	34 (15.5%)
	Not controlled	11 (18.6%)	3 (27.3%)	6 (54.5%)	0 (0.0%)	4 (10.5%)
	Don't know/ Not sure	2 (3.4%)	0 (0.0%)	2 (100.0%)	0 (0.0%)	2 (28.6%)
	Total Missing	11	7	3	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]: 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

Eighty-six percent of those surveyed saw a health care professional for their diabetes, with 49% seeing a diabetes specialist (average number of visits was 2.4 times per year) and 44% seeing a general or family doctor (average number of visits was 2.6 times per year) (see Appendix Table 2.3.1 and 2.3.2).

People were informed about their condition through a variety of channels. Ninety-two percent received information from a doctor or nurse, 47% from the internet, and 44% from a nutritionist, dietician, and diabetes or other health organisation (see Table 2 and Appendix Table 2.4).

Table 2: Source of information regarding diabetes

Information Source	All Respondents (n=62)
Doctor or nurse	57 (91.9%)
Internet	29 (46.8%)
Nutritionist or dietician	27 (43.5%)
Diabetes organisation or other health organisation	27 (43.5%)
TV/Radio/Newspaper/Magazines	18 (29.0%)
Health educator	16 (25.8%)
Social media (e.g. Facebook, Twitter, blogs)	15 (24.2%)
Family/Friends/Neighbours	11 (17.7%)
Pharmacist	10 (16.1%)
None of the above	1 (1.6%)

A range of strategies was used by respondents to manage their diabetes. For those with type 1 diabetes, apart from insulin, 80% managed their diabetes with diet, 50% with exercise, and 20% with oral medicine. Of the respondents with type 2 diabetes, 72% reported that they managed their condition with diet, 69% with oral medicine, 41% with exercise, and 38% with insulin.

Twenty-two percent of respondents were enrolled in diabetes management programmes, and of those 82% said the programme included information on the importance of screening for diabetic eye complications (see Appendix Table 2.6).

The nature and frequency of tests that people with diabetes experienced included blood glucose checks and eye checks. For those who had eye checks (82%), these occurred at the following intervals: less than 6 months (35%), 6 - 12 months (29%), and greater than 12 months (12%) (see Appendix Table 2.7).

The main challenges in controlling diabetes cited by respondents were: the high cost of care (46%), it was too hard to eat the right things (42%), there were too many other things to do (23%), the person did not know enough about their diabetes or did not want to think about having diabetes (16%) (see Appendix Table 2.9).

Free or low cost medicines or monitoring materials (53%), support from family or friends (51%), health education and information (39%), coordination of healthcare and services by a professional (37%), and support groups (20%) were identified as important to improving the management of their diabetes (see Appendix Table 2.10).

Nature and Information about Complications

Eighty-two percent of respondents were aware of vision loss and other complications, such as: amputation (80%), foot ulcers (74%), neuropathy (70%) and cardiovascular disease or stroke (70%) which were also associated with diabetes (see Appendix Table 2.11).

Respondents were most concerned about vision loss (28%), cardiovascular disease or stroke (24%), amputation (19%), kidney disease (11%), and neuropathy (7.4%) (see Appendix Table 2.12).

Thirty-three percent of respondents reported that they had no complications of diabetes. However, of those who did have complications 32% had neuropathy, vision loss (22%), cardiovascular disease or stroke (7.4%), foot ulcers (5.6%), and kidney disease (3.7%) (see Figure 1 and Appendix Table 2.13).

The frequency of neuropathy increased from 30% in those without DED to 38% with DED. The frequency of other complications also increased but the number of respondents was small (see Table 3 and Appendix EXP 1).

Figure 1: Presence of complications

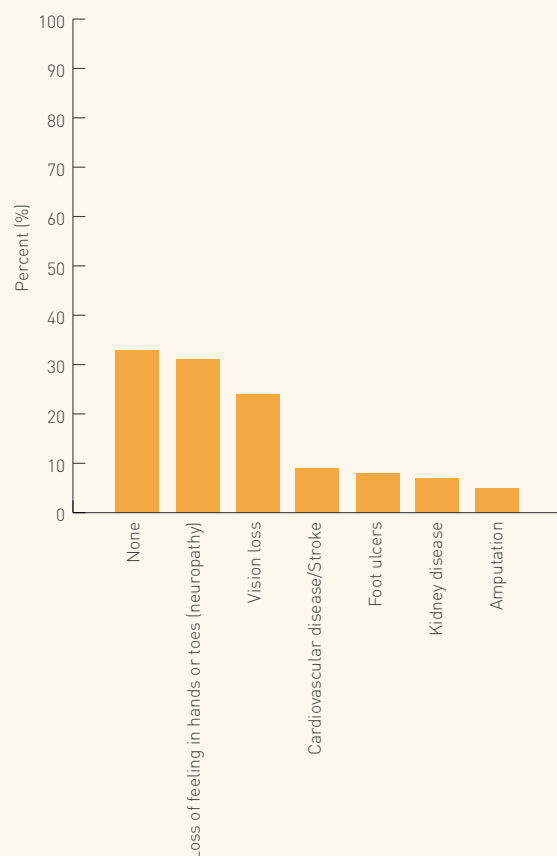


Table 3: Presence of complications without DED, with DED or DME

Complication	Without DED (n=46)	With DME (n=8)
Any	28 (60.9%)	8 (100.0%)
Vision loss	6 (13.0%)	6 (75.0%)
Loss of feeling in hands or toes (neuropathy)	14 (30.4%)	3 (37.5%)
Cardiovascular disease/Stroke	3 (6.5%)	1 (12.5%)
Foot ulcers	2 (4.3%)	1 (12.5%)
Kidney disease	2 (4.3%)	0 (0.0%)
Amputation	1 (2.2%)	0 (0.0%)
Other	0 (0.0%)	0 (0.0%)
None	18 (39.1%)	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]: Percentages within groups are calculated from non-missing data for that question.

NB [4]: 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-eight percent of respondents stated that eye complications were discussed with their health care professionals. Notwithstanding this, over one in three patients (37%) either never discussed eye complications with their providers (15%) or discussions only took place once symptoms arose (22%). The frequency of regular discussions varied from every visit (20%), multiple times a year (9.1%) and for over a quarter (27%) of respondents discussions occurred only once a year (see Appendix Table 2.14).

Eighty percent reported that they did what they could to prevent vision problems (e.g. get routine screenings, visit specialists). Yet myths and perceptions around vision changes and prevention strategies were evident with one in four respondents (26%) thinking that vision problems were a normal part of ageing and some (8%) made no special effort to have a preventative approach to their eye health (see Appendix Table 2.15).

Forty-eight percent of all respondents had received information about DR and DME, with their doctor or nurse being the most common source (30%). A concerning finding was over half (52%) of all respondents did not receive such information from any of the traditional sources listed, such as their doctor or nurse (70%) (see Appendix Table 3.9).

Table 4: Source of information about DR and DME

Information Source	All Respondents (n=50)
Doctor/Nurse	15 (30.0%)
Internet	9 (18.0%)
Diabetes organisation or other health organisation	8 (16.0%)
Health educator	6 (12.0%)
TV/Radio/Newspaper/Magazines	5 (10.0%)
Family/Friends/Neighbours	1 (2.0%)
None of the above	26 (52.0%)

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

Over two-thirds (69%) of respondents reported having an eye exam for DED, with 61% having the exam within the last year and a further 21% between one and two years ago. Eleven percent of respondents were aware of government sponsored screening programmes for DED (see Appendix Table 3.1 and 3.2).

While 73% of those surveyed reported that they should have their eyes examined for DED once a year, a small number of respondents said that testing should happen either every two years, or more, or only when symptoms occur (see Appendix Table 3.4).

The biggest barriers to eye exams, from the patient perspective, were the cost of the exam (47%), a limited access to diabetes specialists (22%), and not wanting to be a burden on their family or friends (20%) (see Table 5 and Appendix Table 3.5).

Table 5: Barriers to eye examinations

Identified Barriers	All Respondents (n=45)
They are expensive	21 (46.7%)
Limited access to diabetes specialists	10 (22.2%)
Burden on my family/friends	9 (20.0%)
Long wait time for appointment	8 (17.8%)
Eye exams are not available near my home	6 (13.3%)
Too many other things to do or worry about	5 (11.1%)
Fear of treatment/results	4 (8.9%)
Long wait time on the day of the visit	3 (6.7%)
Clinics are too small or lack necessary equipment/staff	3 (6.7%)
Referral process is complicated or takes too long	2 (4.4%)
Recommended treatments for eye problems are not available	2 (4.4%)
Don't know much about my condition	1 (2.2%)
Other	4 (8.9%)

Treatment of Diabetic Eye Disease and Diabetic Macular Edema

Those with DED, half had received treatment with the most common being laser treatment (100%) and anti-VEGF therapy (75%). All patients with DED, who received treatment, completed their treatment(s) and felt it had been successful and their vision had either improved (n=2) or had stayed the same (n=2) (see Table 6).

For the two respondents (25%) with DED who had not received treatment, the reasons reported were their doctor did not recommend any treatment or they thought treatment would not be effective.

Table 6: Treatment characteristics of patients with DED and DME

Question	Response	With DED (n=8)
Have you had any treatment for diabetic eye disease?	Yes	4 (50.0%)
	No	2 (25.0%)
	Don't know/Not sure	2 (25.0%)
What treatment did you receive?	Laser	4 (100.0%)
	Anti-VEGF	3 (75.0%)
	Surgery	2 (50.0%)
Did you complete the treatment?	Yes	4 (100.0%)
Do you feel that the treatment worked?	Yes, and vision improved	2 (50.0%)
	Yes, but vision stayed the same	2 (50.0%)
What are the reason(s) that you have not had treatment for diabetic eye disease?	My doctor did not recommend any treatment	1 (50.0%)
	Treatment would not be effective	1 (50.0%)

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

NB [2]: Not all respondents answered all questions in the survey; percentages are calculated from non-missing responses to the survey question.

NB [3]: 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

Eighty-eight percent of those diagnosed with DED said that their vision was affected (38% significantly, 50% slightly) (see Appendix Table 3.6).

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

Table 7: Activities affected through vision impairment and loss

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

Thirty-eight percent of those with DED were in paid employment compared with 56% of respondents without DED (see Table 8 and EXP 5.1). Over half (57%) of those with DED and corresponding vision complications reported difficulties with working or keeping a job.

While seventy percent of all those surveyed did not receive assistance from the government, 28% of all respondents did receive pension assistance. Sixty-five percent of respondents said they had no trouble paying for food at any time during the past year. There was a marked increase in those with DED receiving government assistance and experiencing difficulty paying for food in the last year compared to those without DED although the sample is notably small (see Appendix Table 4.5 and 4.6).

Although 40% of respondents stated their access to healthcare was not affected by any influencing factors, 38% believed it was affected by their income, 19% felt their race affected their access to healthcare, and 12% reported where they lived was an influencing factor (see Appendix Table 4.7).

Health (48%), money (38%), and family (15%) were the top three 'worries' on the minds of the respondents surveyed (see Appendix Table 4.8).

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

Question	Response	Without DED (n=45)	With DED (n=8)
Are you currently working?	Working for pay	25 (55.6%)	3 (37.5%)
	Working without pay at home (e.g. housework, farming)	3 (6.7%)	0 (0.0%)
	Volunteering	0 (0.0%)	2 (25.0%)
	Retired	11 (24.4%)	3 (37.5%)
	Student	2 (4.4%)	0 (0.0%)
	Not working	4 (8.9%)	0 (0.0%)
Question	Response	Without DED (n=44)	With DED (n=5)
Do you receive assistance from the government?	Medical assistance	1 (2.3%)	1 (16.7%)
	Pension assistance	12 (27.3%)	2 (33.3%)
	None of the above	31 (70.5%)	4 (66.7%)
Question	Response	Without DED (n=44)	With DED (n=5)
Did you have trouble paying for food at any time during the past year?	Yes	15 (34.1%)	2 (40.0%)
	No	29 (65.9%)	3 (60.0%)

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]: 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.

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 slightly depending on whether respondents had been diagnosed with, or without, DED (see Table 9).

Compared with 29% of those without DED, 71% of people with DED experienced limitations to their daily activities due to poor health. Where health impacted daily activities, the primary limitations were, diabetes, walking problems and back or neck problems (see EXP 2).

People living with DED had a higher proportion for some impairments. Of note were walking problems, hypertension or high blood pressure, and fractures, bone or joint injury. These patients have complex comorbidities that require careful management across the health and social care system.

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

Health Status	Without DED	With DED
Self-rated health: Good	19 (46.3%)	3 (60.0%)
Self-rated health: Poor	22 (53.7%)	2 (40.0%)
Physically unhealthy days	19 (51.4%)	2 (40.0%)
Mentally unhealthy days	18 (50.0%)	2 (66.7%)
Unhealthy days	27 (73.0%)	3 (100.0%)
Activity limitation days	12 (42.9%)	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]: 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.

South Africa

DR Barometer Findings:

Health Care Professionals

Key Demographic Characteristics

There were 68 health care professionals who answered at least one of the survey questions in South Africa. Of these, five were primary care providers (7.4%), nine were diabetes specialist providers (13%) and 17 were ophthalmologists (25%). The remaining respondents were optometrists, nurses, health educators or other types of professionals (see Appendix PT 1.3).

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

Health care professionals as a group had been practicing for an average of 20 years, with the ophthalmologist group practicing for an average of 14 years (see Appendix PT 1.5).

Health care professionals were well educated (71% with graduate or advanced degree); 58% were female and 42% male and, varied in age categories with 40% in the 50 - 59 year 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		68 (100.0%)	5 (7.4%)	9 (13.2%)	17 (25.0%)
Age group	18 - 29 yrs.	1 (2.2%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	30 - 39 yrs.	5 (11.1%)	0 (0.0%)	1 (14.3%)	3 (18.8%)
	40 - 49 yrs.	13 (28.9%)	1 (25.0%)	2 (28.6%)	6 (37.5%)
	50 - 59 yrs.	18 (40.0%)	1 (25.0%)	1 (14.3%)	5 (31.3%)
	60 - 69 yrs.	6 (13.3%)	1 (25.0%)	2 (28.6%)	2 (12.5%)
	70 - 79 yrs.	2 (4.4%)	1 (25.0%)	1 (14.3%)	0 (0.0%)
Gender	Female	26 (57.8%)	2 (50.0%)	3 (42.9%)	5 (31.3%)
	Male	19 (42.2%)	2 (50.0%)	4 (57.1%)	11 (68.8%)
Education	College/University	13 (28.9%)	3 (75.0%)	0 (0.0%)	2 (12.5%)
	Graduate or advanced degree (e.g. PhD, MD, etc.)	32 (71.1%)	1 (25.0%)	7 (100.0%)	14 (87.5%)

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

Seventy-seven of all providers had their main practice in an eye clinic and for ophthalmologists the settings were an eye clinic (77%) and a hospital (24%). Eighty-five percent of health care professionals worked in an urban setting (see Appendix PT 2.1 and PT 2.2).

Most health care professionals worked in the private sector (58%) and ophthalmologists worked mainly in the private (71%) and government (29%) sectors (see Appendix PT 2.3).

The health care professionals reported that 34% of patients pay out-of-pocket (full fees) for services, 34% pay some and insurance pays the remaining fee for services, and 32% do not pay for services. The pattern was similar for ophthalmologists, where 44% of patients pay some and insurance pays the remaining fee for services, 38% pay through insurance for services, and 31% do not pay for services (see Appendix PT 2.7).

On average, all providers saw 71 patients per week and an estimated 36% had diabetes. Similarly, ophthalmologists saw an average 82 patients per week and 30% had diabetes (see Appendix PT 2.6).

For all health care professionals, the average waiting time for an appointment was most commonly less than one week (34%), or between one week and a month (18%) (see Table 11 and Appendix PT 2.5).

For an appointment with ophthalmologist, it was usually between one week and a month in 31% of practices, but for a further quarter of practices, the wait time was between one and two months.

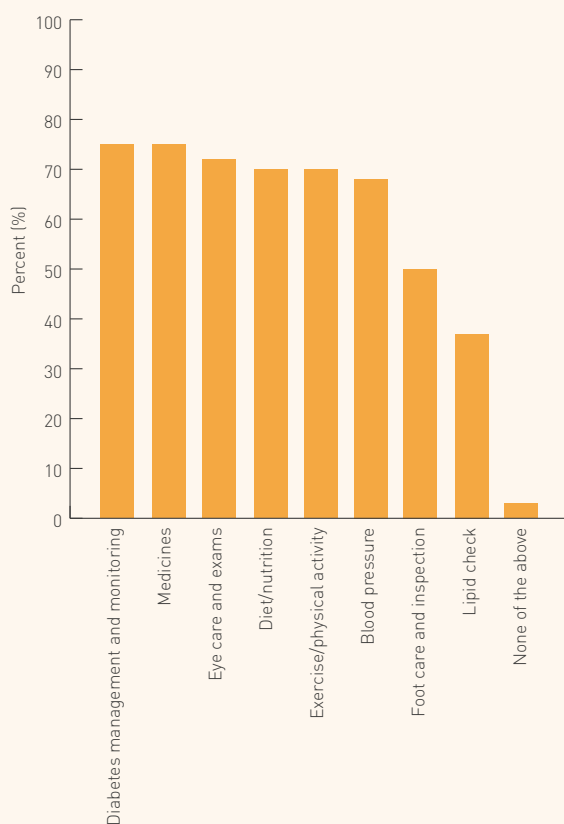
Table 11: Average wait times to schedule an appointment

Wait Time Intervals	All Respondents (n=50)	Ophthalmologist (n=16)
Less than 1 week	17 (34.0%)	2 (12.5%)
More than 1 week but less than 1 month	9 (18.0%)	5 (31.3%)
More than 1 month but less than 2 months	6 (12.0%)	4 (25.0%)
More than 2 months but less than 3 months	4 (8.0%)	2 (12.5%)
More than 3 months but less than 6 months	3 (6.0%)	1 (6.3%)
Six or more months	1 (2.0%)	1 (6.3%)
Do not take appointments	4 (8.0%)	1 (6.3%)
Other	6 (12.0%)	0 (0.0%)

Patient Education Information

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

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



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

Overall, half (50%) of all providers surveyed, including 39% of ophthalmologists, had no written information on diabetes and potential eye complications available for their patients. Almost a third (31%) of all providers had some information but it was deemed insufficient. Only 18% percent of all providers reported that they had sufficient information about eye complications (see Table 12 and Appendix PT 2.11).

Only 26% of ophthalmologists had sufficient information about diabetes and potential eye complications, while 28% had information on eye complications, which was considered insufficient. Overall, 43% of ophthalmologists did not have any written information regarding eye complications available for their patients.

Guidelines and Protocols

Fifty-four percent of providers had written protocols and guidelines for the management of diabetes, which were used by staff. However, 37% of all providers, including 69% of ophthalmologists, had no protocols available for reference on the management of diabetes (see Appendix PT 2.12).

With respect to the management of diabetes-related vision issues, 50% of all providers, including ophthalmologists, did not have any written protocols available. Of those who did, 30% of health care professionals, including only 13% of ophthalmologists, had written protocols, which were used by staff and for some 31%, the protocols, which were available were not used by staff (see Table 12 and Appendix PT 2.13).

Table 12: Availability and use of information and protocols

Question	Response	All Respondents (n=46)	Ophthalmologist (n=16)
Is there written information about diabetes available for patients in your main practice?	Yes, and information on eye complications is sufficient	12 (26.1%)	3 (18.8%)
	Yes, but information on eye complications is not sufficient	13 (28.3%)	5 (31.3%)
	Yes, but no information on eye complications is included	2 (4.3%)	0 (0.0%)
	No written information is available for patients	18 (39.1%)	8 (50.0%)
	Don't know/Not sure	1 (2.2%)	0 (0.0%)
Question	Response	All Respondents (n=46)	Ophthalmologist (n=16)
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	14 (30.4%)	2 (12.5%)
	Yes, available but not used by staff	6 (13.0%)	5 (31.3%)
	Not available	23 (50.0%)	8 (50.0%)
	Don't know/Not sure	3 (6.5%)	1 (6.3%)

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

Screening Protocols and Barriers in the Care Pathway

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

For those with type 1 diabetes, 41% of all providers reported that the initial eye exam should occur at time of the diagnosis of diabetes, however 21% reported there was no standard practice and recommendations varied on a case-by-case basis. For patients with type 2 diabetes, 72% of all providers recommended an eye exam at time of diagnosis (see Appendix PT 2.14).

Overall, seventy-one percent of health care professionals, including 81% of ophthalmologists, reported that follow-up eye examinations were conducted every year. There is some disquiet in the finding that 8.9% of providers recommend follow-up screening only when symptoms are present. All ophthalmologists and most of the health care professionals (73%), screen patients for DR (see Appendix PT 2.15 and PT 2.16).

Close to half (49%) of all providers, including 38% of ophthalmologists, reported that they send their patients reminders to schedule follow-up appointments. Overall, 91% shared patient relevant information with other providers to optimize patient care management (see Appendix PT 2.19 and PT 2.20).

The most common patient characteristics influencing the referral process for eye complications were: the duration of diabetes (72%), the presence of comorbidities such as hypertension (63%), high glucose levels (61%), and a patient's age (56%) (see Appendix PT 2.17).

As reported by all health care professionals, the major barriers to optimizing eye health faced by patients with diabetes was a lack of knowledge or awareness on behalf of the patient (58%), the referral process (54%), and the cost of care (49%). Ophthalmologists like health care professionals reported similar such barriers (see Table 13 and Appendix PT 2.18).

Table 13: Major barriers to optimising eye health

Response	All Respondents (n=43)	Ophthalmologists (n=16)
Lack of knowledge and/or awareness	25 (58.1%)	11 (68.8%)
Referral process	23 (53.5%)	9 (56.3%)
Cost of care	21 (48.8%)	7 (43.8%)
Proximity to care	14 (32.6%)	6 (37.5%)
Limited access to diabetes specialists	15 (34.9%)	6 (37.5%)
Limited access to eye specialists	19 (44.2%)	4 (25.0%)
Long wait time for appointment	11 (25.6%)	3 (18.8%)
Long wait time on the day of visit	11 (25.6%)	3 (18.8%)
Patients feel eye complications are unlikely	8 (18.6%)	3 (18.8%)
Patients have competing responsibilities and priorities	11 (25.6%)	3 (18.8%)
Clinic too small or lack necessary equipment/staff	6 (14.0%)	3 (18.8%)
Recommended treatments are not available	6 (14.0%)	2 (12.5%)
Patients fear of treatment/results	7 (16.3%)	2 (12.5%)
Patients feel they are a burden on family/friends	5 (11.6%)	1 (6.3%)
Patients feel eye exams are not important	9 (20.9%)	1 (6.3%)
Other	2 (4.7%)	1 (6.3%)

South Africa

DR Barometer Findings:

Ophthalmologists

Screening

There were sixteen ophthalmologists who answered at least one of the supplementary questions (see Appendix PT 4.1 to PT 4.14). On average, 26% of patients seen by ophthalmologists had DR and 20% had DME (see Appendix PT 4.1 and PT 4.2).

The most common waiting time for a patient for a screening appointment for DED was between one week and a month (38%), with a quarter of ophthalmologists stating between one and two months (see Appendix PT 4.3).

Eighty-eight percent of ophthalmologists reported that there was no wait from time of screening to diagnosis (see Appendix PT 4.4).

Treatment and Challenges

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

The most common factors influencing the how ophthalmologists treat patients with DR or DME were: the presence of comorbidities such as hypertension (57%), high glucose levels (50%), and the duration of diabetes (36%) (see Appendix PT 4.7).

The most common outreach venues for screening for DED were vision centres (31%), health fairs for people with diabetes (19%), health fairs for all (6.3%), and mobile screening centres (6.3%). It should be noted that 44% of ophthalmologist reported to not conduct outreach (see Appendix PT 4.13).

Eighty percent of ophthalmologists reported that they screen patients for DR based on fundoscopy through dilated pupils, 33% based on retinal photo, and 33% based on optical coherence tomography. Eighty-seven percent said that they treat DR and DME based on both visual and anatomical outcomes (see Appendix PT 4.8 and PT 4.9).

Seventy-three percent reported that patients present when visual problems have already occurred, 20% (n=3) reported that patients present in time for screening, and 6.7% (n=1) said that patients present too late for effective treatment although the sample is notably small (see Appendix PT 4.10).

Seventy-five percent of ophthalmologists had received specific training on treatment and diagnosis of DR and or DME. A third had received training within the past year, 17% between one and five years ago while one-quarter received training five years ago or more (see Appendix PT 4.11).

Nonetheless, 94% of all ophthalmologists would be interested in online education and certification on DME, angiogenesis and anti-VEGF therapies (see Appendix PT 4.12).

Ophthalmologists reported that the greatest challenges for improving patient outcomes in DED were the referral pathways (69%), late diagnosis (56%), and poor multi-disciplinary team integration (56%) (see Table 15 and Appendix PT 4.14).

Table 14: Challenges for improving outcomes in DED

Question	Response	Ophthalmologist (n=16)
What do you perceive to be the greatest challenges for improving patient outcomes in diabetic eye disease?	Referral pathways	11 (68.8%)
	Late diagnosis	9 (56.3%)
	Multi-disciplinary team integration is poor	9 (56.3%)
	Limited access to patient education on diabetic retinopathy and diabetic macular edema	7 (43.8%)
	No universal guidelines on referral/screening	6 (37.5%)
	Ineffective screening services	6 (37.5%)
	Reimbursement/restrictions on approved therapy	4 (25.0%)
	No universal guidelines on how to treat	1 (6.3%)
	No universal guideline on when to treat	1 (6.3%)
	Current available therapies not effective	1 (6.3%)
	Government/insurance not able to cover patient costs	1 (6.3%)
	Other	2 (12.5%)

South Africa

DR Barometer Summary

In South Africa, 70 adults with diabetes and 68 health care professionals have provided insight about their experiences of living with, managing and treating diabetes, DR and DME. The results help to improve awareness, management, and services available in South Africa.

A further 17% of respondents were either unsure of or did not know their type of diabetes (see Appendix Table 2.1).

South Africa is estimated to be the fifth most populous country in Africa with a population of approximately 54.3 million inhabitants and has the highest number of people living with diabetes in the region at ~2.3 million (1,163.7-4,620.6±), which accounts to ~16% of people living with diabetes in this region^{4,5}.

By 2050, the population distribution in South Africa is expected to increase by 33%. However, there will be a decrease in the percentage of those 15 and younger (21%) and a drastic increase of 165% for those aged 65 years or older. In just over 30 years the population of 65 years or older will reach an all-time high of approximately 7.5 million, ~10% of the population with an increase in life expectancy to ~69 years of age.

The African region has the highest proportion of estimated undiagnosed diabetes (66.7%), which accounts to ~9.5 million people living in this region whom are unaware that they may have diabetes. Of the 14.2 million living with diabetes, over half (58.8%) live in cities, even though the population in the region is predominantly (61.3%) rural.

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. This is an important, and well-known, finding in the context of South Africa's rapidly ageing population.

People were most often informed about their diabetes condition from their health care providers, such as a doctor, nurse, nutritionist, or dietician although diabetes or other health organisations were also identified as important sources of information. A trend globally, and reflected in the South Africa study, was the increasing usage of the internet by almost half (47%) of the respondents.

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, acknowledging their diabetic condition, and seeking additional information to understand and manage their diabetes. These three factors could play a role in the finding that only twenty-two percent of respondents were currently enrolled in a diabetes management programme. The greatest challenge reported, which was beyond their control, was the cost of care.

Although there was a relatively high awareness of the various complications associated with diabetes, along with a majority of respondents experiencing at least one of these complications there was still a relatively low concern regarding the onset of complications yet vision loss was feared most. There was a noted increase in the frequency of those with DED experiencing certain complications compared with people with DED, although the sample size was small.

The relationship between the patient and their provider is critical to realistic and optimal patient outcomes. Indeed, health education and information was reported by over a third of patients as an important tool to improve the management of one's diabetes yet an astounding 70% of patients did not receive any information on potential eye complications from their doctor or nurse. Likewise, over half of all providers (58%) reported the greatest barrier for optimising eye health was a lack of knowledge or awareness on behalf of the patient and yet only 18% percent of all providers reported that they had sufficient information about eye complications available for their patients.

It is also important to note that over one in three (37%) of those surveyed had either never had a conversation about potential eye complications with their doctors or did so only after symptoms arose. Equally concerning is the myths and perceptions around vision changes and prevention strategies, with one in four respondents thinking that vision problems were a normal part of ageing and some made no special effort to have a preventative approach to their eye health.

Knowledge and guidance was not only an issue for patients, as half of all providers, including ophthalmologists, did not have written protocols or guidelines available for the management of diabetes-related vision issues.

Of the adults with diabetes who responded to the survey in South Africa, 11% (n=8) reported to be diagnosed with DED and no one had been diagnosed with DME. Eighty-six percent of those diagnosed with DED said that their vision was affected slightly, or significantly, which in turn affected their health, lifestyle, and life choices. One in two (57%) reported that their ability to work or keep a job was put in jeopardy. Forty-three percent had trouble driving a vehicle or enjoying leisure activities, including exercising.

For more than a quarter (29%), their vision loss resulted in difficulties interacting with family and friends, conducting household responsibilities such as cooking or cleaning and even affected their ability to manage their underlying diabetes. There was a reported 42% increase in those with DED who experienced limitations to their daily activities due to poor health compared to those without DED.

Although 40% of respondents stated their access to healthcare was not affected by any influencing factors, 38% believed it was affected by their income, 19% felt their race affected their access to healthcare, and 12% reported where they lived was an influencing factor. Health, money, and family were the top three 'worries' on the minds of the respondents surveyed.

Supporting this, health care professionals cited cost of care (49%) and one's proximity to care (33%) as two significant barriers patients faced in optimising their eye health. Patients also reported the cost of exam (47%) and the limited access to diabetes specialists (22%) as barriers they face, which may reflect that one's income and where one lives could impact their access to certain healthcare.

Knowing that diabetes-related vision loss is preventable, addressing barrier to eye screening is an important policy issue. While most respondents had received an eye exam, which is understandable considering the purposeful sample, there still remained many barriers.

Reported barriers were primarily associated with the health system, clinical capacities, and the high cost of care, such as a complicated referral process, long wait times to schedule an appointment, and eye exams are considered expensive by almost half (47%) of the patients surveyed. In addition, given that the majority of ophthalmologists recommend annual screening for DED, it was a surprise finding that only 38% send reminders to their patients to schedule follow-up appointments.

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

Almost three-quarters (73%) of ophthalmologists reported that the majority of their patients present for screening when visual problems had already occurred rather in time for screening. Furthermore, over half (56%) reported late diagnosis as one of the greatest challenges in improving patient outcomes for those with DED and DME along with the referral pathways and poor multi-disciplinary integration across health care professions.

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

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

References and Acknowledgement

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Appendices



The Diabetic Retinopathy Barometer Survey: Appendices for South Africa

APPENDIX 1 : National Results

Table 1.1

Survey Information	Number of Respondents (%)
All valid respondents [1]	88 (100.0%)
Respondents aged 18 or over	84 (95.5%)
Respondents with diabetes	70 (79.5%)

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

Table 1.2

Survey Information	Number of Respondents (%)
All valid respondents	88 (100.0%)
Included in Diabetic Analysis Set	70 (79.5%)
Excluded from Diabetic Analysis Set	18 (20.5%)
Reasons for exclusion from diabetic analysis set	.
Under 18 years of age	4
Not diagnosed with diabetes	10
Missing information on diabetes diagnosis	4

Table 1.3

Survey Information	Number of Respondents (%)
Diabetic Analysis Set	70 (100.0%)
World Bank Income Group: Upper-middle income	70 (100.0%)
Persons with diabetic eye disease (DED)	8 (11.4%)
Persons with Type I diabetes	23 (32.9%)
Persons with Type II diabetes	35 (50.0%)
Persons not seeing health care professional for diabetes	9 (12.9%)
Persons seeing health care professional for diabetes	56 (80.0%)
Persons with eye disease & not received treatment	2 (2.9%)
Persons with eye disease & received treatment	4 (5.7%)

Table 2.1

Question	Response	Number of Respondents (%)
With which type of diabetes have you been diagnosed?	Type I	23 (32.9)
	Type II	35 (50.0)
	Don't know/Not sure	12 (17.1)
	Total Valid Response	70 (100.0)

Table 2.2

Question	Response	Number of Respondents (%)
When was your diabetes diagnosed?	Within the last year	2 (3.1)
	1 - 5 years ago	19 (29.2)
	6 - 10 years ago	13 (20.0)
	11 - 15 years ago	11 (16.9)
	16 - 20 years ago	5 (7.7)
	21 years ago or longer	12 (18.5)
	Don't know/Not sure	3 (4.6)
	Total Valid Response	65 (100.0)
	Total missing	5

Table 2.3.1

Question	Response	Number of Respondents (%)
Do you see a health care professional for your diabetes?	Yes	56 (86.2)
	No	9 (13.8)
	Total Valid Response	65 (100.0)
	Total missing	5
What kind of health care professional?	General/Family Doctor	24 (43.6)
	Nurse	2 (3.6)
	Diabetes Specialist	27 (49.1)
	Other	1 (1.8)
	Don't know/Not sure of kind	1 (1.8)

Question	Response	Number of Respondents (%)
	Total Valid Response	55 (100.0)
	Total missing	15

Table 2.3.2

Type of health care professional	Times per year seen for diabetes	Value
General/Family Doctor	Total valid numeric response (n)	23
	Mean	2.6
	SD	2.1
	Median	2.0
	Min	1
	Max	10
	Don't know/Not sure	1
Nurse	Total valid numeric response (n)	0
	Mean	
	SD	
	Median	
	Min	
	Max	
	Don't know/Not sure	1
	Total missing	1
Diabetes Specialist	Total valid numeric response (n)	21
	Mean	2.4
	SD	1.1
	Median	2.0
	Min	1
	Max	4
	Total missing	6
Other	Total valid numeric response (n)	0
	Mean	
	SD	
	Median	
	Min	
	Max	

Type of health care professional	Times per year seen for diabetes	Value
	Total missing	1
Don't know/Not sure of kind	Don't know/Not sure	1

Table 2.4

Question	Response	Number of Respondents (%)
How have you received information about diabetes?	Doctor or nurse	57 (91.9%)
	Health educator	16 (25.8%)
	Nutritionist or dietitian	27 (43.5%)
	Diabetes organization or other health organization	27 (43.5%)
	Family/Friends/Neighbors	11 (17.7%)
	TV/Radio/Newspaper/Magazines	18 (29.0%)
	Internet	29 (46.8%)
	Social media (e.g. Facebook, Twitter, blogs)	15 (24.2%)
	Pharmacist	10 (16.1%)
	None of the above	1 (1.6%)
	Total Valid Response	62 (100.0%)
	Total missing	8

Table 2.5

Question	Response	Number of Respondents (%)
How do you manage your diabetes?	Diet	47 (74.6%)
	Oral medicine	32 (50.8%)
	Exercise	27 (42.9%)
	Insulin	34 (54.0%)
	Natural/Herbal medicine	5 (7.9%)
	Total Valid Response	63 (100.0%)
	Total missing	7

Table 2.6

Question	Response	Number of Respondents (%)
Are you currently enrolled in a diabetes patient management support programme?	Yes	14 (22.2)
	No	49 (77.8)
	Total Valid Response	63 (100.0)
	Total missing	7
Who sponsors the programme?	Hospital support program	1 (8.3)
	Clinic support program	3 (25.0)
	Pharmaceutical support program	1 (8.3)
	Don't know/Not sure	7 (58.3)
	Total Valid Response	12 (100.0)
	Total missing	58
Does the programme include education on the importance of screening for diabetic eye complications?	Yes	9 (81.8)
	No	2 (18.2)
	Total Valid Response	11 (100.0)
	Total missing	59

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	56 (98.2%)
	Less than 6 months	39 (68.4%)
	6 - 12 months	7 (12.3%)
	Greater than 12 months	8 (14.0%)
	Total valid response	54 (94.7%)
	Total missing	16
	No	1 (1.8%)
	Total valid	57 (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	13
Urine check	Yes	53 (98.1%)
	Less than 6 months	31 (57.4%)
	6 - 12 months	11 (20.4%)
	Greater than 12 months	7 (13.0%)
	Total valid response	49 (90.7%)
	Total missing	21
	No	1 (1.9%)
	Total valid response	54 (100.0%)
	Total missing	16
Weight check	Yes	49 (90.7%)
	Less than 6 months	29 (53.7%)
	6 - 12 months	16 (29.6%)
	Greater than 12 months	1 (1.9%)
	Total valid response	46 (85.2%)
	Total missing	24
	No	5 (9.3%)
	Total valid response	54 (100.0%)
	Total missing	16
Blood pressure check	Yes	55 (98.2%)
	Less than 6 months	45 (80.4%)
	6 - 12 months	7 (12.5%)
	Total valid response	52 (92.9%)

Test	Response	Number of Respondents (%)
Have you ever had the following tests in a doctors office of clinic? And if yes, how long ago		
	Total missing	18
	No	1 (1.8%)
	Total valid response	56 (100.0%)
	Total missing	14
Foot check	Yes	31 (62.0%)
	Less than 6 months	19 (38.0%)
	6 - 12 months	6 (12.0%)
	Greater than 12 months	3 (6.0%)
	Total valid response	28 (56.0%)
	Total missing	42
	No	19 (38.0%)
	Total valid response	50 (100.0%)
	Total missing	20
Eye check	Yes	42 (82.4%)
	Less than 6 months	18 (35.3%)
	6 - 12 months	15 (29.4%)
	Greater than 12 months	6 (11.8%)
	Total valid response	39 (76.5%)
	Total missing	31
	No	7 (13.7%)
	Don't know/Not sure	2 (3.9%)
	Total valid response	51 (100.0%)
	Total missing	19

Table 2.8

Question	Response	Number of Respondents (%)
How well do you think your diabetes is controlled?	Very well	19 (32.2%)
	Well	27 (45.8%)
	Not very well	9 (15.3%)
	Not well at all	2 (3.4%)
	Don't know/Not sure	2 (3.4%)
	Total Valid Response	59 (100.0%)
	Total missing	11

Table 2.9

Question	Response	Number of Respondents (%)
What are the main challenges you face in controlling your diabetes?	High cost of care	26 (45.6%)
	No insurance	8 (14.0%)
	Travel to my regular doctor or specialist is difficult	7 (12.3%)
	Long wait time for an appointment to see my doctor or specialist	5 (8.8%)
	Health services needed are not available	6 (10.5%)
	Don't know enough about diabetes	9 (15.8%)
	Too hard to eat the right things	24 (42.1%)
	Too many other things to do	13 (22.8%)
	Stigma or discrimination because of diabetes	3 (5.3%)
	Don't want to think about having diabetes	9 (15.8%)
	Other	10 (17.5%)
	Total Valid Response	57 (100.0%)
	Total missing	13

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	27 (52.9%)
	Support groups	10 (19.6%)
	Support from family or friends	26 (51.0%)
	Health education and information	20 (39.2%)
	Mobile services (services that travel to or near your home)	1 (2.0%)
	Coordination of healthcare and services by a professional	19 (37.3%)
	Emergency helpline	4 (7.8%)
	Other	4 (7.8%)
	None	3 (5.9%)
	Total Valid Response	51 (100.0%)
	Total missing	19

Table 2.11

Question	Response	Number of Respondents (%)
What complications (or problems), to your knowledge, arise from diabetes?	Amputation	43 (79.6%)
	Foot ulcers	40 (74.1%)
	Increased risk of broken bones or fractures	12 (22.2%)
	Loss of feeling in hands or toes (neuropathy)	38 (70.4%)
	Vision loss	44 (81.5%)
	Irritable bowel disease	19 (35.2%)
	Kidney disease	36 (66.7%)
	Cardiovascular disease/Stroke	38 (70.4%)
	Other	8 (14.8%)
	None	2 (3.7%)
	Total Valid Response	54 (100.0%)
	Total missing	16

Table 2.12

Question	Response	Number of Respondents (%)
Which complication of diabetes are you most concerned about?	Amputation	10 (18.5)
	Foot ulcers	2 (3.7)
	Loss of feeling in hands or toes (neuropathy)	4 (7.4)
	Vision loss	15 (27.8)
	Irritable bowel disease	1 (1.9)
	Kidney disease	6 (11.1)
	Cardiovascular disease/Stroke	13 (24.1)
	None	3 (5.6)
	Total Valid Response	54 (100.0)
	Total missing	16

Table 2.13

Question	Response	Number of Respondents (%)
Which of the following complications of diabetes do you have?	Amputation	1 (1.9%)
	Foot ulcers	3 (5.6%)
	Loss of feeling in hands or toes (neuropathy)	17 (31.5%)
	Vision loss	12 (22.2%)
	Irritable bowel disease	8 (14.8%)
	Kidney disease	2 (3.7%)
	Cardiovascular disease/Stroke	4 (7.4%)
	Don't know/Not sure	4 (7.4%)
	None	18 (33.3%)
	Total Valid Response	54 (100.0%)
	Total missing	16

Table 2.14

Question	Response	Number of Respondents (%)
How often do you discuss the possibility of eye	Every visit	11 (20.0%)

Question	Response	Number of Respondents (%)
complications with your health care professional?		
	Multiple times per year	5 (9.1%)
	Once per year	15 (27.3%)
	Only when symptoms arise	12 (21.8%)
	Never	8 (14.5%)
	Don't know/Not sure	4 (7.3%)
	Total Valid Response	55 (100.0%)
	Total missing	15

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	13 (26.0%)
	I do what I can to prevent vision problems (e.g. get routine screenings, visit specialists)	40 (80.0%)
	I do not make any special effort to prevent vision problems	4 (8.0%)
	Total Valid Response	50 (100.0%)
	Total missing	20

Table 2.16

Question	Response	Number of Respondents (%)
What type of health insurance do you have?	Public	3 (5.8)
	Public - Private	1 (1.9)
	Private	36 (69.2)
	None	12 (23.1)
	Total Valid Response	52 (100.0)
	Total missing	18

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	8 (16.0)
	Insurance pays total cost	13 (26.0)
	Insurance and out-of-pocket/cash (e.g. co-pays)	21 (42.0)
	Out-of-pocket only (pay cash for all care)	8 (16.0)
	Total Valid Response	50 (100.0)
	Total missing	20
Specialist medical visits (e.g. eye doctor, gynecologist, urologist)	Care is free	2 (4.5)
	Insurance pays total cost	9 (20.5)
	Insurance and out-of-pocket/cash (e.g. co-pays)	25 (56.8)
	Out-of-pocket only (pay cash for all care)	6 (13.6)
	Do not use service	2 (4.5)
	Total Valid Response	44 (100.0)
	Total missing	26
Medicines	Care is free	9 (18.4)
	Insurance pays total cost	6 (12.2)
	Insurance and out-of-pocket/cash (e.g. co-pays)	29 (59.2)
	Out-of-pocket only (pay cash for all care)	5 (10.2)
	Total Valid Response	49 (100.0)
	Total missing	21
Medical supplies (e.g. blood glucose meter/strips)	Care is free	6 (13.3)
	Insurance pays total cost	15 (33.3)
	Insurance and out-of-pocket/cash (e.g. co-pays)	16 (35.6)
	Out-of-pocket only (pay cash for all care)	8 (17.8)

Question	Response	Number of Respondents (%)
Most often, how do you pay for the following types of medical care and services?		
	Total Valid Response	45 (100.0)
	Total missing	25
Procedures	Care is free	1 (2.3)
	Insurance pays total cost	7 (15.9)
	Insurance and out-of-pocket/cash (e.g. co-pays)	26 (59.1)
	Out-of-pocket only (pay cash for all care)	7 (15.9)
	Do not use service	3 (6.8)
	Total Valid Response	44 (100.0)
	Total missing	26
Tests/screenings	Care is free	2 (4.4)
	Insurance pays total cost	13 (28.9)
	Insurance and out-of-pocket/cash (e.g. co-pays)	21 (46.7)
	Out-of-pocket only (pay cash for all care)	7 (15.6)
	Do not use service	2 (4.4)
	Total Valid Response	45 (100.0)
	Total missing	25
Health education	Care is free	11 (25.0)
	Insurance pays total cost	8 (18.2)
	Insurance and out-of-pocket/cash (e.g. co-pays)	6 (13.6)
	Out-of-pocket only (pay cash for all care)	7 (15.9)
	Do not use service	12 (27.3)
	Total Valid Response	44 (100.0)
	Total missing	26
Counseling	Care is free	6 (14.0)
	Insurance pays total cost	6 (14.0)
	Insurance and out-of-pocket/cash (e.g. co-pays)	9 (20.9)

Question	Response	Number of Respondents (%)
Most often, how do you pay for the following types of medical care and services?		
	Out-of-pocket only (pay cash for all care)	5 (11.6)
	Do not use service	15 (34.9)
	Don't know/Not Sure	2 (4.7)
	Total Valid Response	43 (100.0)
	Total missing	27

Table 3.1

Question	Response	Number of Respondents (%)
Are you aware of any government sponsored screening programs for diabetic eye disease (diabetic retinopathy)?	Yes	6 (11.1%)
	No	48 (88.9%)
	Total valid response	54 (100.0%)
	Total missing	16

Table 3.2

Question	Response	Number of Respondents (%)
Have you ever had an eye exam for diabetic eye disease?	Yes	38 (69.1%)
	No	17 (30.9%)
	Total valid response	55 (100.0%)
	Total missing	15
How long ago was your last eye exam?	Within the last year	23 (60.5%)
	More than 1 year ago but less than 2 years	8 (21.1%)
	More than 2 years ago but less than 3 years	4 (10.5%)
	More than 3 years ago but less than 5 years	2 (5.3%)
	Five or more years ago	1 (2.6%)
	Total valid response	38 (100.0%)

Question	Response	Number of Respondents (%)
	Total missing	32
Who did the last exam?	General/Family practitioner	1 (2.7%)
	Eye doctor/Eye clinic	33 (89.2%)
	Other	2 (5.4%)
	Don't know/Not sure	1 (2.7%)
	Total valid response	37 (100.0%)
	Total missing	33

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	32 (59.3%)
	No	17 (31.5%)
	Don't know/Not sure	5 (9.3%)
	Total valid response	54 (100.0%)
	Total missing	16

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	38 (73.1%)
	Every two years	6 (11.5%)
	Less often than every two years	1 (1.9%)
	Only when symptoms occur	4 (7.7%)
	Never	1 (1.9%)
	Don't know/Not sure	2 (3.8%)
	Total valid response	52 (100.0%)
	Total missing	18

Table 3.5

Question	Response	Number of Respondents (%)
For you, what are the biggest barriers to eye exams?	They are expensive	21 (46.7%)
	Eye exams are not available near my home	6 (13.3%)
	Long wait time for appointment	8 (17.8%)
	Long wait time on the day of the visit	3 (6.7%)
	Referral process is complicated or takes too long	2 (4.4%)
	Recommended treatments for eye problems are not available	2 (4.4%)
	Don't know much about my condition	1 (2.2%)
	Fear of treatment/results	4 (8.9%)
	Burden on my family/friends	9 (20.0%)
	Limited access to diabetes specialists	10 (22.2%)
	Too many other things to do or worry about	5 (11.1%)
	Clinics are too small or lack necessary equipment/staff	3 (6.7%)
	Other	4 (8.9%)
	Total valid response	45 (100.0%)
	Total missing	25

Table 3.6

Question	Response	Number of Respondents (%)
Have you been diagnosed with diabetic eye disease?	Yes	8 (15.1%)
	No	45 (84.9%)
	Total valid response	53 (100.0%)
	Total missing	17
Has your diabetic eye disease affected your vision?	Yes, slightly	4 (50.0%)
	Yes, significantly	3 (37.5%)
	No	1 (12.5%)
	Total valid response	8 (100.0%)
	Total missing	62

Question	Response	Number of Respondents (%)
Have vision issues caused you to have difficulty with any of the following?	Traveling	2 (28.6%)
	Household responsibilities, such as cooking or cleaning	2 (28.6%)
	Social interactions with family/friends	2 (28.6%)
	Leisure activities/exercise	3 (42.9%)
	Work or keeping a job	4 (57.1%)
	Managing my diabetes	2 (28.6%)
	Other	2 (28.6%)
	None	1 (14.3%)
	Driving (a car/vehicle)	3 (42.9%)
	Total valid response	7 (100.0%)
	Total missing	63

Table 3.7

Question	Response	Number of Respondents (%)
Have you had any treatment for diabetic eye disease?	Yes	4 (50.0%)
	No	2 (25.0%)
	Don't know/Not sure	2 (25.0%)
	Total valid response	8 (100.0%)
	Total missing	62
What treatment did you receive?	Laser	4 (100.0%)
	Injection in the eye (Anti-VEGF)	3 (75.0%)
	Surgery	2 (50.0%)
	Total valid response	4 (100.0%)
	Total missing	66
Did you complete the treatment?	Yes	4 (100.0%)
	Total valid response	4 (100.0%)
	Total missing	66
Do you feel that the treatment worked?	Yes, and vision improved	2 (50.0%)
	Yes, but vision stayed the	2 (50.0%)

Question	Response	Number of Respondents (%)
	same	
	Total valid response	4 (100.0%)
	Total missing	66
What is/are the reason(s) that you did not complete the treatment?	Total missing	70
What are the reason(s) that you have not had treatment for diabetic eye disease?	My doctor did not recommend any treatment	1 (50.0%)
	Treatment would not be effective	1 (50.0%)
	Total valid response	2 (100.0%)
	Total missing	68

Table 3.8

Question	Response	Number of Respondents (%)
Have you been diagnosed with diabetic macular edema?	No	44 (84.6%)
	Don't know/Not sure	8 (15.4%)
	Total valid response	52 (100.0%)
	Total missing	18
If Yes, which of the following would you prefer	Total missing	70

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 (30.0%)
	Health educator	6 (12.0%)
	Diabetes organization or other health organization	8 (16.0%)
	Family/Friends/Neighbors	1 (2.0%)
	TV/Radio/Newspaper/Magazines	5 (10.0%)
	Internet	9 (18.0%)

Question	Response	Number of Respondents (%)
	None of the above	26 (52.0%)
	Total valid response	50 (100.0%)
	Total missing	20

Table 4.1

Question	Response	Number of Respondents (%)
What is your gender?	Female	41 (82.0)
	Male	9 (18.0)
	Total Valid Response	50 (100.0)
	Total missing	20
Please indicate your age	18 - 29	6 (8.6)
	30 - 39	14 (20.0)
	40 - 49	9 (12.9)
	50 - 59	14 (20.0)
	60 - 69	20 (28.6)
	70 - 79	6 (8.6)
	80 - 89	1 (1.4)
	Total Valid Response	70 (100.0)

Table 4.2

Question	Response	Number of Respondents (%)
Where do you live?	Urban setting	40 (80.0)
	Non-urban setting	10 (20.0)
	Total Valid Response	50 (100.0)
	Total missing	20

Table 4.3

Question	Response	Number of Respondents (%)
What is the highest level of education you completed?	Primary school	1 (2.1)
	Secondary school	19 (40.4)
	College/University	10 (21.3)

Question	Response	Number of Respondents (%)
	Graduate or post-graduate	17 (36.2)
	Total valid response	47 (100.0)
	Total missing	23

Table 4.4

Question	Response	Number of Respondents (%)
Are you currently working?	Working for pay	28 (52.8)
	Working without pay at home (e.g. housework, farming)	3 (5.7)
	Volunteering	2 (3.8)
	Retired	14 (26.4)
	Student	2 (3.8)
	Not working	4 (7.5)
	Total Valid Response	53 (100.0)
	Total missing	17

Table 4.5

Question	Response	Number of Respondents (%)
Do you receive assistance from the government?	Medical assistance	2 (4.0%)
	Pension assistance	14 (28.0%)
	None of the above	35 (70.0%)
	Total valid response	50 (100.0%)
	Total missing	20

Table 4.6

Question	Response	Number of Respondents (%)
Did you have trouble paying for food at anytime during the past year?	Yes	17 (34.7)
	No	32 (65.3)

Question	Response	Number of Respondents (%)
	Total Valid Response	49 (100.0)
	Total missing	21

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	1 (2.4)
	Education	1 (2.4)
	Ethnicity	4 (9.5)
	Gender	1 (2.4)
	Income	16 (38.1)
	Language you speak	4 (9.5)
	Place of birth	1 (2.4)
	Place where you live	5 (11.9)
	Race	8 (19.0)
	None of the above	21 (50.0)
	Total valid response	42 (100.0)
	Total missing	28

Table 4.8

Question	Response	Number of Respondents (%)
Which of the following do you worry about most?	Food	1 (2.1)
	Housing	2 (4.2)
	Money	18 (37.5)
	Health	19 (39.6)
	Family	7 (14.6)
	None of the above	1 (2.1)
	Total Valid	48 (100.0)

Question	Response	Number of Respondents (%)
	Response	
	Total missing	22

Table 5.1

Question	Response	Number of Respondents (%)
In general, would you say your health is:	Very good	10 (21.7%)
	Good	12 (26.1%)
	Total good health	22 (47.8%)
	Fair	18 (39.1%)
	Poor	6 (13.0%)
	Fair or poor health	24 (52.2%)
	Total valid response	46 (100.0%)
	Total missing	24

Table 5.2

Question	Response	Number of Respondents (%)
How many days during last 30 days was your physical health not good	Any unhealthy days	21 (50.0%)
	1-5 unhealthy days	10 (23.8%)
	6-10 unhealthy days	3 (7.1%)
	11-20 unhealthy days	6 (14.3%)
	21-30 unhealthy days	2 (4.8%)
	No unhealthy days	21 (50.0%)
	Total valid response	42 (100.0%)
	Total missing	28

Table 5.3.1

Question	Response	Number of Respondents (%)
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Question	Response	Number of Respondents (%)
How many days during last 30 days was your mental health not good	Any unhealthy days	20 (51.3%)
	1-5 unhealthy days	8 (20.5%)
	6-10 unhealthy days	6 (15.4%)
	11-20 unhealthy days	5 (12.8%)
	21-30 unhealthy days	1 (2.6%)
	No unhealthy days	19 (48.7%)
	Total valid response	39 (100.0%)
	Total missing	31

Table 5.3.2

Question	Response	Number of Respondents (%)
Unhealthy days (physically or mentally unhealthy, max 30)	Any unhealthy days	30 (75.0%)
	1-5 unhealthy days	8 (20.0%)
	6-10 unhealthy days	6 (15.0%)
	11-20 unhealthy days	10 (25.0%)
	21-30 unhealthy days	6 (15.0%)
	No unhealthy days	10 (25.0%)
	Total valid response	40 (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	14 (42.4%)

Question	Response	Number of Respondents (%)
	1-5 unhealthy days	7 (21.2%)
	6-10 unhealthy days	3 (9.1%)
	11-20 unhealthy days	4 (12.1%)
	No unhealthy days	19 (57.6%)
	Total valid response	33 (100.0%)
	Total missing	37

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	18 (40.9%)
	No	26 (59.1%)
	Total valid response	44 (100.0%)
	Total missing	26
Which impairment or health problem, if any, limits your activities?		
a) Arthritis/rheumatism	Yes	5 (29.4%)
	No	11 (64.7%)
	Don't know/Not sure	1 (5.9%)
	Total valid response	17 (100.0%)
	Total missing	53
b) Back or neck problem	Yes	9 (52.9%)
	No	8 (47.1%)
	Total valid response	17 (100.0%)
	Total missing	53
c) Fractures, bone/joint injury	Yes	8 (53.3%)
	No	7 (46.7%)

Question	Response	Number of Respondents (%)
	Total valid response	15 (100.0%)
	Total missing	55
d) Walking problem	Yes	11 (61.1%)
	No	7 (38.9%)
	Total valid response	18 (100.0%)
	Total missing	52
e) Lung/breathing problem	Yes	2 (10.5%)
	No	17 (89.5%)
	Total valid response	19 (100.0%)
	Total missing	51
f) Hearing problem	Yes	2 (11.1%)
	No	16 (88.9%)
	Total valid response	18 (100.0%)
	Total missing	52
g) Eye/vision problem	Yes	4 (21.1%)
	No	15 (78.9%)
	Total valid response	19 (100.0%)
	Total missing	51
h) Heart problem	Yes	1 (5.6%)
	No	17 (94.4%)
	Total valid response	18 (100.0%)
	Total missing	52
i) Stroke problem	Yes	2 (11.1%)
	No	16 (88.9%)
	Total valid response	18 (100.0%)
	Total missing	52
j) Hypertension/high blood pressure	Yes	7 (41.2%)
	No	9 (52.9%)

Question	Response	Number of Respondents (%)
	Don't know/Not sure	1 (5.9%)
	Total valid response	17 (100.0%)
	Total missing	53
k) Diabetes	Yes	18 (85.7%)
	No	3 (14.3%)
	Total valid response	21 (100.0%)
	Total missing	49
l) Cancer	Yes	2 (10.5%)
	No	17 (89.5%)
	Total valid response	19 (100.0%)
	Total missing	51
m) Mental or emotional health	Yes	6 (33.3%)
	No	12 (66.7%)
	Total valid response	18 (100.0%)
	Total missing	52

PT 1.2

Analysis Sets	Number of Respondents (%)
All valid respondents	68 (100.0%)
Included in Provider Analysis Set (PAS)	68 (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	68
Included in the Eye Care Professional Set (Eye Specialist)	23 (33.8%)
Excluded in the Eye Care Professional Set (Eye Specialist)	45 (66.2%)
Reasons for exclusion from Eye Care Professional Set:	.
Missing required speciality	45

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

PT 1.3

Subgroups	Number of Respondents (%)
Provider Analysis Set	68 (100.0%)
Primary Care Provider	5 (7.4%)
Diabetes Specialist Provider	9 (13.2%)
Eye Care Professional	23 (33.8%)
Ophthalmologist	17 (25.0%)

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

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

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

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

PT 1.4

Item	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
What is your specialty?	General primary care/Family practitioner	5 (100.0%)	1 (11.1%)	1 (5.9%)	7 (10.3%)
	Diabetes specialist	0 (0.0%)	9 (100.0%)	0 (0.0%)	9 (13.2%)
	General ophthalmologist	0 (0.0%)	0 (0.0%)	13 (76.5%)	13 (19.1%)
	Optometrist	0 (0.0%)	0 (0.0%)	0 (0.0%)	6 (8.8%)
	Retinal specialist	0 (0.0%)	0 (0.0%)	5 (29.4%)	5 (7.4%)
	Nurse	3 (60.0%)	0 (0.0%)	0 (0.0%)	23 (33.8%)
	Health educator	1 (20.0%)	0 (0.0%)	0 (0.0%)	5 (7.4%)
	None of the above	0 (0.0%)	0 (0.0%)	0 (0.0%)	9 (13.2%)
	Total valid response	5 (100.0%)	9 (100.0%)	17 (100.0%)	68 (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)	5	9	17	68
	Mean	30.6	19.9	14.1	20.2
	SD	13.3	15.2	9.0	13.7
	Median	30.0	14.0	14.0	18.0
	Min.	14	3	0	0
	Max.	47	40	33	56
	Total missing	0	0	0	0

PT 2.1

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
What is your main practice setting?	Diabetes clinic/practice	0 (0.0%)	6 (66.7%)	0 (0.0%)	8 (13.3%)
	Eye clinic/practice	1 (25.0%)	0 (0.0%)	13 (76.5%)	19 (31.7%)
	General medical clinic/practice	3 (75.0%)	2 (22.2%)	0 (0.0%)	9 (15.0%)
	Hospital	0 (0.0%)	1 (11.1%)	4 (23.5%)	8 (13.3%)
	Other	0 (0.0%)	0 (0.0%)	0 (0.0%)	16 (26.7%)
	Total Valid Response	4 (100.0%)	9 (100.0%)	17 (100.0%)	60 (100.0%)
	Total missing	1	0	0	8

PT 2.2

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Where is your main practice located?	Urban setting	4 (100.0%)	8 (88.9%)	12 (70.6%)	50 (84.7%)
	Non-urban setting	0 (0.0%)	1 (11.1%)	5 (29.4%)	9 (15.3%)

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Total Valid Response	4 (100.0%)	9 (100.0%)	17 (100.0%)	59 (100.0%)
	Total missing	1	0	0	9

PT 2.3

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
In which sector is your main practice?	Government	1 (25.0%)	3 (33.3%)	5 (29.4%)	13 (22.0%)
	Private	2 (50.0%)	5 (55.6%)	12 (70.6%)	34 (57.6%)
	Non profit	1 (25.0%)	1 (11.1%)	0 (0.0%)	10 (16.9%)
	Combined/mixed	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (3.4%)
	Total Valid Response	4 (100.0%)	9 (100.0%)	17 (100.0%)	59 (100.0%)
	Total missing	1	0	0	9

PT 2.4

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Is your main practice limited to certain populations?	No	3 (75.0%)	4 (44.4%)	11 (68.8%)	33 (55.9%)
	Yes, limited by age	0 (0.0%)	2 (22.2%)	0 (0.0%)	13 (22.0%)
	Yes, limited by gender	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (1.7%)
	Yes, limited to persons with health insurance	0 (0.0%)	3 (33.3%)	3 (18.8%)	7 (11.9%)
	Yes, limited to low income or uninsured persons	0 (0.0%)	1 (11.1%)	2 (12.5%)	4 (6.8%)

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Yes, limited to persons who pay out-of-pocket	0 (0.0%)	0 (0.0%)	2 (12.5%)	4 (6.8%)
	Yes, other	1 (25.0%)	0 (0.0%)	0 (0.0%)	2 (3.4%)
	Total valid response	4 (100.0%)	9 (100.0%)	16 (100.0%)	59 (100.0%)
	Total missing	1	0	1	9

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	4 (100.0%)	3 (42.9%)	2 (12.5%)	17 (34.0%)
	More than 1 week but less than 1 month	0 (0.0%)	1 (14.3%)	5 (31.3%)	9 (18.0%)
	More than 1 month but less than 2 months	0 (0.0%)	1 (14.3%)	4 (25.0%)	6 (12.0%)
	More than 2 months but less than 3 months	0 (0.0%)	1 (14.3%)	2 (12.5%)	4 (8.0%)
	More than 3 months but less than 6 months	0 (0.0%)	1 (14.3%)	1 (6.3%)	3 (6.0%)
	Six or more months	0 (0.0%)	0 (0.0%)	1 (6.3%)	1 (2.0%)
	Do not take appointments	0 (0.0%)	0 (0.0%)	1 (6.3%)	4 (8.0%)
	Other	0 (0.0%)	0 (0.0%)	0 (0.0%)	6 (12.0%)
	Total Valid Response	4 (100.0%)	7 (100.0%)	16 (100.0%)	50 (100.0%)
	Total missing	1	2	1	18

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	7	16	48
	Mean	71	148.6	82.4	71.3
	SD	87.7	142.2	42.1	74.2
	Median	40	80	85	51
	Min.	4	30	20	1
	Max.	200	400	170	400
	Total missing	1	2	1	20
What percentage of the patients in your main practice have diabetes [% patients]	Total valid response (n)	3	7	15	44
	Mean	13.7	69.3	30.3	36.1
	SD	5.5	33	21.9	32.9
	Median	11	70	25	22.5
	Min.	10	10	10	2
	Max.	20	100	85	100
	Total missing	2	2	2	24

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	2 (50.0%)	3 (42.9%)	5 (31.3%)	16 (32.0%)
	Pay a reduced/subsidized rate	1 (25.0%)	4 (57.1%)	4 (25.0%)	12 (24.0%)
	Pay out-of-pocket (full fees)	0 (0.0%)	2 (28.6%)	5 (31.3%)	17 (34.0%)

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Pay through insurance	0 (0.0%)	4 (57.1%)	6 (37.5%)	14 (28.0%)
	Patient pays some, insurance pays some	1 (25.0%)	4 (57.1%)	7 (43.8%)	17 (34.0%)
	Other	0 (0.0%)	0 (0.0%)	1 (6.3%)	3 (6.0%)
	Total valid response	4 (100.0%)	7 (100.0%)	16 (100.0%)	50 (100.0%)
	Total missing	1	2	1	18

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%)	4 (57.1%)	6 (37.5%)	16 (32.0%)
	No	3 (75.0%)	3 (42.9%)	10 (62.5%)	34 (68.0%)
	Total valid response	4 (100.0%)	7 (100.0%)	16 (100.0%)	50 (100.0%)
	Total missing	1	2	1	18
In which other practice setting(s) do you work?	Hospital		2 (50.0%)	2 (33.3%)	4 (25.0%)
	General medical clinic/practice		1 (25.0%)		1 (6.3%)
	Diabetes clinic/practice	1 (100.0%)			2 (12.5%)
	Eye clinic/practice			4 (66.7%)	5 (31.3%)
	Other		1 (25.0%)		4 (25.0%)
	Total valid response	1 (100.0%)	4 (100.0%)	6 (100.0%)	16 (100.0%)
	Total missing	4	5	11	52
In which sector(s) is(are) the	Government		1 (33.3%)	2 (33.3%)	3 (20.0%)

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
practice(s)?					
	Private	1 (100.0%)	2 (66.7%)	3 (50.0%)	9 (60.0%)
	Non profit				2 (13.3%)
	Combined/mixed				1 (6.7%)
	Total valid response	1 (100.0%)	3 (100.0%)	6 (100.0%)	15 (100.0%)
	Total missing	4	6	11	53
Is there a major difference between your practices with respect to how diabetic eye disease is screened and managed?	Yes	1 (100.0%)	3 (75.0%)	2 (33.3%)	7 (43.8%)
	No		1 (25.0%)	4 (66.7%)	9 (56.3%)
	Total valid response	1 (100.0%)	4 (100.0%)	6 (100.0%)	16 (100.0%)
	Total missing	4	5	11	52

PT 2.9

Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Blood glucose	Yes		3 (100.0%)	7 (100.0%)	8 (50.0%)	33 (73.3%)
		Total valid numeric response (n)	3 (100.0%)	7 (100.0%)	8 (50.0%)	32 (71.1%)
		Mean	71.3	4.7	2.5	68.1
		SD	111.5	3.3	4.1	133.5
		Median	12.0	4.0	1.0	4.0
		Min	2	2	0	0
		Max	200	12	12	365
		Total missing	2	2	9	36

Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	No				8 (50.0%)	12 (26.7%)
	Total valid response		3 (100.0%)	7 (100.0%)	16 (100.0%)	45 (100.0%)
	Total missing		2	2	1	23
HbA1c	Yes		1 (33.3%)	7 (100.0%)	7 (43.8%)	23 (54.8%)
		Total valid numeric response (n)	1 (33.3%)	7 (100.0%)	7 (43.8%)	23 (54.8%)
		Mean	3.0	3.0	0.7	2.1
		SD		1.0	1.1	1.6
		Median	3.0	3.0	0.0	2.0
		Min	3	2	0	0
		Max	3	4	3	6
		Total missing	4	2	10	45
	No		2 (66.7%)		9 (56.3%)	19 (45.2%)
	Total valid response		3 (100.0%)	7 (100.0%)	16 (100.0%)	42 (100.0%)
	Total missing		2	2	1	26
Urine check	Yes		3 (100.0%)	7 (100.0%)	3 (18.8%)	27 (60.0%)
		Total valid numeric response (n)	3 (100.0%)	7 (100.0%)	3 (18.8%)	25 (55.6%)
		Mean	38.3	2.4	5.3	12.0
		SD	53.6	1.3	6.1	21.6
		Median	12.0	2.0	4.0	4.0
		Min	3	1	0	0
		Max	100	4	12	100
		Total	2	2	14	43

Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
		missing				
	No				13 (81.3%)	18 (40.0%)
	Total valid response		3 (100.0%)	7 (100.0%)	16 (100.0%)	45 (100.0%)
	Total missing		2	2	1	23
Weight check	Yes		3 (100.0%)	7 (100.0%)	3 (18.8%)	29 (64.4%)
		Total valid numeric response (n)	3 (100.0%)	7 (100.0%)	3 (18.8%)	26 (57.8%)
		Mean	8.3	3.6	2.3	6.0
		SD	4.7	0.8	2.1	5.6
		Median	10.0	4.0	3.0	4.0
		Min	3	2	0	0
		Max	12	4	4	24
		Total missing	2	2	14	42
	No				13 (81.3%)	16 (35.6%)
	Total valid response		3 (100.0%)	7 (100.0%)	16 (100.0%)	45 (100.0%)
	Total missing		2	2	1	23
Blood pressure check	Yes		3 (100.0%)	7 (100.0%)	5 (31.3%)	32 (69.6%)
		Total valid numeric response (n)	3 (100.0%)	7 (100.0%)	5 (31.3%)	29 (63.0%)
		Mean	38.3	4.3	1.2	16.4
		SD	53.6	3.6	1.6	23.9
		Median	12.0	4.0	1.0	4.0
		Min	3	1	0	0
		Max	100	12	4	100

Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
		Total missing	2	2	12	39
	No				11 (68.8%)	14 (30.4%)
	Total valid response		3 (100.0%)	7 (100.0%)	16 (100.0%)	46 (100.0%)
	Total missing		2	2	1	22
	Foot check		Yes	3 (100.0%)	7 (100.0%)	2 (12.5%)
		Total valid numeric response (n)	3 (100.0%)	7 (100.0%)	2 (12.5%)	24 (53.3%)
		Mean	7.0	2.0	2.0	12.3
		SD	4.6	1.0	2.8	19.3
		Median	6.0	2.0	2.0	2.5
		Min	3	1	0	0
		Max	12	4	4	56
		Total missing	2	2	15	44
	No				14 (87.5%)	19 (42.2%)
	Total valid response		3 (100.0%)	7 (100.0%)	16 (100.0%)	45 (100.0%)
	Total missing		2	2	1	23
Eye examination - Un-dilated	Yes		2 (66.7%)	3 (42.9%)	8 (50.0%)	22 (53.7%)
		Total valid numeric response (n)	2 (66.7%)	3 (42.9%)	8 (50.0%)	22 (53.7%)
		Mean	9.0	2.0	1.1	19.5
		SD	4.2	1.7	1.1	77.3
		Median	9.0	1.0	1.0	1.5
		Min	6	1	0	0

Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
		Max	12	4	3	365
		Total missing	3	6	9	46
		No	1 (33.3%)	4 (57.1%)	8 (50.0%)	19 (46.3%)
		Total valid response	3 (100.0%)	7 (100.0%)	16 (100.0%)	41 (100.0%)
		Total missing	2	2	1	27
		Yes	1 (33.3%)	1 (14.3%)	11 (68.8%)	13 (31.7%)
Eye examination - Optical Coherence Tomography	Yes					
		Total valid numeric response (n)	1 (33.3%)	1 (14.3%)	11 (68.8%)	13 (31.7%)
		Mean	0.0	1.0	1.6	1.5
		SD			2.9	2.7
		Median	0.0	1.0	1.0	1.0
		Min	0	1	0	0
		Max	0	1	10	10
		Total missing	4	8	6	55
		No	2 (66.7%)	6 (85.7%)	5 (31.3%)	28 (68.3%)
		Total valid response	3 (100.0%)	7 (100.0%)	16 (100.0%)	41 (100.0%)
		Total missing	2	2	1	27
		Yes	2 (66.7%)	6 (85.7%)	16 (100.0%)	31 (73.8%)
		Eye examination - Fundoscopy				
		Total valid numeric response (n)	2 (66.7%)	6 (85.7%)	16 (100.0%)	31 (73.8%)
		Mean	3.5	1.5	1.8	13.4

Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
		SD	3.5	1.2	2.5	65.3
		Median	3.5	1.0	1.0	1.0
		Min	1	1	0	0
		Max	6	4	10	365
		Total missing	3	3	1	37
	No		1 (33.3%)	1 (14.3%)		11 (26.2%)
	Total valid response		3 (100.0%)	7 (100.0%)	16 (100.0%)	42 (100.0%)
	Total missing		2	2	1	26
	Eye examination - Fluorescein Angiography	Yes			10 (62.5%)	10 (24.4%)
		Total valid numeric response (n)	0 (0.0%)	0 (0.0%)	10 (62.5%)	10 (24.4%)
		Mean			0.8	0.8
		SD			0.9	0.9
		Median			0.5	0.5
		Min			0	0
		Max			2	2
		Total missing	5	9	7	58
	No		3 (100.0%)	7 (100.0%)	6 (37.5%)	31 (75.6%)
	Total valid response		3 (100.0%)	7 (100.0%)	16 (100.0%)	41 (100.0%)
	Total missing		2	2	1	27
Eye examination - Lipid check	Yes			4 (57.1%)	5 (31.3%)	12 (28.6%)
		Total valid	0 (0.0%)	4 (57.1%)	5 (31.3%)	12

Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
		numeric response (n)				(28.6%)
		Mean		1.3	0.6	0.9
		SD		0.5	0.9	0.7
		Median		1.0	0.0	1.0
		Min		1	0	0
		Max		2	2	2
		Total missing	5	5	12	56
	No		3 (100.0%)	3 (42.9%)	11 (68.8%)	30 (71.4%)
	Total valid response		3 (100.0%)	7 (100.0%)	16 (100.0%)	42 (100.0%)
	Total missing		2	2	1	26

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%)	7 (100.0%)	10 (62.5%)	35 (76.1%)
	Diet/nutrition	4 (100.0%)	7 (100.0%)	6 (37.5%)	32 (69.6%)
	Exercise/physical activity	4 (100.0%)	7 (100.0%)	5 (31.3%)	32 (69.6%)
	Medicines	3 (75.0%)	7 (100.0%)	9 (56.3%)	35 (76.1%)
	Foot care and inspection	4 (100.0%)	6 (85.7%)	1 (6.3%)	24 (52.2%)
	Blood pressure	4 (100.0%)	6 (85.7%)	7 (43.8%)	31 (67.4%)
	Eye care and	3 (75.0%)	6 (85.7%)	14 (87.5%)	33

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	exams				(71.7%)
	Lipid check	2 (50.0%)	6 (85.7%)	4 (25.0%)	18 (39.1%)
	None of the above	0 (0.0%)	0 (0.0%)	1 (6.3%)	1 (2.2%)
	Total valid response	4 (100.0%)	7 (100.0%)	16 (100.0%)	46 (100.0%)
	Total missing	1	2	1	22

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%)	3 (42.9%)	3 (18.8%)	12 (26.1%)
	Yes, but information on eye complications is not sufficient	1 (25.0%)	2 (28.6%)	5 (31.3%)	13 (28.3%)
	Yes, but no information on eye complications is included	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (4.3%)
	No written information is available for patients	1 (25.0%)	1 (14.3%)	8 (50.0%)	18 (39.1%)
	Don't know/Not sure	0 (0.0%)	1 (14.3%)	0 (0.0%)	1 (2.2%)
	Total Valid Response	4 (100.0%)	7 (100.0%)	16 (100.0%)	46 (100.0%)
	Total missing	1	2	1	22

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	3 (75.0%)	6 (85.7%)	2 (12.5%)	25 (54.3%)
	Yes, available but not used by staff	0 (0.0%)	0 (0.0%)	3 (18.8%)	3 (6.5%)
	Not available	1 (25.0%)	1 (14.3%)	11 (68.8%)	17 (37.0%)
	Don't know/Not sure	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (2.2%)
	Total Valid Response	4 (100.0%)	7 (100.0%)	16 (100.0%)	46 (100.0%)
	Total missing	1	2	1	22

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%)	4 (57.1%)	2 (12.5%)	14 (30.4%)
	Yes, available but not used by staff	0 (0.0%)	1 (14.3%)	5 (31.3%)	6 (13.0%)
	Not available	2 (50.0%)	2 (28.6%)	8 (50.0%)	23 (50.0%)
	Don't know/Not sure	0 (0.0%)	0 (0.0%)	1 (6.3%)	3 (6.5%)
	Total Valid	4	7 (100.0%)	16 (100.0%)	46

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Response	(100.0%)			(100.0%)
	Total missing	1	2	1	22

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 exams for persons with diabetes - Type I?	After a predetermined number of years (numeric response) (n)	0 (0.0%)	4 (57.1%)	1 (7.1%)	7 (15.9%)
	Mean		5.0	5.0	5.0
	SD		0.0		0.0
	Median		5.0	5.0	5.0
	Min		5	5	5
	Max		5	5	5
	After a predetermined age (numeric response) (n)	0 (0.0%)	0 (0.0%)	3 (21.4%)	4 (9.1%)
	Mean			14.0	11.8
	SD			2.6	5.0
	Median			13.0	12.5
	Min			12	5
	Max			17	17
	As soon as they are diagnosed	3 (75.0%)	2 (28.6%)	8 (57.1%)	18 (40.9%)
	When a patient reports eye/vision problems			1 (7.1%)	3 (6.8%)
	No standard practice, timing varies case by case	1 (25.0%)	1 (14.3%)	1 (7.1%)	9 (20.5%)
	Don't know/Not				2 (4.5%)

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	sure				
	Other				1 (2.3%)
	Total valid response	4 (100.0%)	7 (100.0%)	14 (100.0%)	44 (100.0%)
	Total missing	1	2	3	24
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				
	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%)	6 (85.7%)	14 (87.5%)	33 (71.7%)
	When a patient reports eye/vision problems		1 (14.3%)	1 (6.3%)	3 (6.5%)
	No standard practice, timing varies case by case			1 (6.3%)	7 (15.2%)
	Don't know/Not sure				2 (4.3%)
	Other				1 (2.2%)

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Total valid response	4 (100.0%)	7 (100.0%)	16 (100.0%)	46 (100.0%)
	Total missing	1	2	1	22

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%)	7 (100.0%)	13 (81.3%)	32 (71.1%)
	Every two years	1 (25.0%)	0 (0.0%)	1 (6.3%)	6 (13.3%)
	Only when symptoms are present	0 (0.0%)	0 (0.0%)	1 (6.3%)	4 (8.9%)
	Other	1 (25.0%)	0 (0.0%)	1 (6.3%)	2 (4.4%)
	Don't know/Not sure	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (2.2%)
	Total Valid Response	4 (100.0%)	7 (100.0%)	16 (100.0%)	45 (100.0%)
	Total missing	1	2	1	23

PT 2.16

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Do you screen patients for DR?	Yes	3 (75.0%)	6 (85.7%)	16 (100.0%)	33 (73.3%)
	No	1 (25.0%)	1 (14.3%)		12 (26.7%)
	Total valid response	4 (100.0%)	7 (100.0%)	16 (100.0%)	45 (100.0%)
	Total missing	1	2	1	23
Where do you	In clinic	2 (66.7%)	5 (83.3%)	15 (100.0%)	28

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
screen patients?					(87.5%)
	Outreach			1 (6.7%)	3 (9.4%)
	Other	2 (66.7%)	1 (16.7%)	1 (6.7%)	5 (15.6%)
	Total valid response	3 (100.0%)	6 (100.0%)	15 (100.0%)	32 (100.0%)
	Total missing	2	3	2	36

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	4 (100.0%)	6 (85.7%)	11 (73.3%)	31 (72.1%)
	Patient's age	4 (100.0%)	6 (85.7%)	4 (26.7%)	24 (55.8%)
	Patient's gender	0 (0.0%)	1 (14.3%)	1 (6.7%)	3 (7.0%)
	Presence of comorbidities such as hypertension, etc.	3 (75.0%)	6 (85.7%)	9 (60.0%)	27 (62.8%)
	High glucose levels	3 (75.0%)	6 (85.7%)	7 (46.7%)	26 (60.5%)
	Ability or inability to pay	0 (0.0%)	1 (14.3%)	2 (13.3%)	5 (11.6%)
	Insurance restrictions	0 (0.0%)	1 (14.3%)	2 (13.3%)	3 (7.0%)
	Patient educational level	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (4.7%)
	Patient adherence to recommendations	1 (25.0%)	0 (0.0%)	1 (6.7%)	7 (16.3%)
	None of the above	0 (0.0%)	1 (14.3%)	2 (13.3%)	4 (9.3%)
	Not applicable	0 (0.0%)	0 (0.0%)	2 (13.3%)	4 (9.3%)
	Total valid response	4 (100.0%)	7 (100.0%)	15 (100.0%)	43 (100.0%)
	Total missing	1	2	2	25

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	2 (50.0%)	2 (40.0%)	7 (43.8%)	21 (48.8%)
	Proximity to care	0 (0.0%)	2 (40.0%)	6 (37.5%)	14 (32.6%)
	Long wait time for appointment	0 (0.0%)	1 (20.0%)	3 (18.8%)	11 (25.6%)
	Long wait time on the day of visit	0 (0.0%)	2 (40.0%)	3 (18.8%)	11 (25.6%)
	Referral process	3 (75.0%)	2 (40.0%)	9 (56.3%)	23 (53.5%)
	Recommended treatments are not available	1 (25.0%)	0 (0.0%)	2 (12.5%)	6 (14.0%)
	Lack of knowledge and/or awareness	2 (50.0%)	2 (40.0%)	11 (68.8%)	25 (58.1%)
	Patients fear of treatment/results	1 (25.0%)	3 (60.0%)	2 (12.5%)	7 (16.3%)
	Patients they are a burden on family/friends	1 (25.0%)	1 (20.0%)	1 (6.3%)	5 (11.6%)
	Limited access to diabetes specialists	1 (25.0%)	0 (0.0%)	6 (37.5%)	15 (34.9%)
	Limited access to eye specialists	1 (25.0%)	3 (60.0%)	4 (25.0%)	19 (44.2%)
	Patients feel eye complications are unlikely	0 (0.0%)	0 (0.0%)	3 (18.8%)	8 (18.6%)
	Patients feel eye exams are not important	0 (0.0%)	0 (0.0%)	1 (6.3%)	9 (20.9%)
	Patients have competing responsibilities and priorities	1 (25.0%)	1 (20.0%)	3 (18.8%)	11 (25.6%)

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Clinic too small or lack necessary equipment/staff	0 (0.0%)	1 (20.0%)	3 (18.8%)	6 (14.0%)
	Other	1 (25.0%)	0 (0.0%)	1 (6.3%)	2 (4.7%)
	Total valid response	4 (100.0%)	5 (100.0%)	16 (100.0%)	43 (100.0%)
	Total missing	1	4	1	25

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	2 (50.0%)	3 (42.9%)	6 (37.5%)	22 (48.9%)
	No	2 (50.0%)	4 (57.1%)	10 (62.5%)	23 (51.1%)
	Total Valid Response	4 (100.0%)	7 (100.0%)	16 (100.0%)	45 (100.0%)
	Total missing	1	2	1	23

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	3 (75.0%)	6 (85.7%)	15 (93.8%)	41 (91.1%)
	No	1 (25.0%)	1 (14.3%)	1 (6.3%)	4 (8.9%)
	Total Valid Response	4 (100.0%)	7 (100.0%)	16 (100.0%)	45 (100.0%)
	Total missing	1	2	1	23

PT 3.1

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Please indicate your age:	18 - 29				1 (2.2%)
	30 - 39		1 (14.3%)	3 (18.8%)	5 (11.1%)
	40 - 49	1 (25.0%)	2 (28.6%)	6 (37.5%)	13 (28.9%)
	50 - 59	1 (25.0%)	1 (14.3%)	5 (31.3%)	18 (40.0%)
	60 - 69	1 (25.0%)	2 (28.6%)	2 (12.5%)	6 (13.3%)
	70 - 79	1 (25.0%)	1 (14.3%)		2 (4.4%)
	Total valid response	4 (100.0%)	7 (100.0%)	16 (100.0%)	45 (100.0%)
	Total missing	1	2	1	23
What is your gender?	Female	2 (50.0%)	3 (42.9%)	5 (31.3%)	26 (57.8%)
	Male	2 (50.0%)	4 (57.1%)	11 (68.8%)	19 (42.2%)
	Total valid response	4 (100.0%)	7 (100.0%)	16 (100.0%)	45 (100.0%)
	Total missing	1	2	1	23
What is your highest level of education completed?	College/University	3 (75.0%)		2 (12.5%)	13 (28.9%)
	Graduate or advanced degree (e.g. PhD, MD, etc)	1 (25.0%)	7 (100.0%)	14 (87.5%)	32 (71.1%)
	Total valid response	4 (100.0%)	7 (100.0%)	16 (100.0%)	45 (100.0%)
	Total missing	1	2	1	23

PT 4.1

Question	Response	Ophthalmologist
What percentage of your patients have diabetic retinopathy	Total valid numeric response (n)	16

Question	Response	Ophthalmologist
	Mean	25.8
	SD	26.9
	Median	17.5
	Min	1
	Max	80
	Total missing	1

PT 4.2

Question	Response	Ophthalmologist
What percentage of your patients have diabetic macular edema?	Total valid numeric response (n)	15
	Mean	19.8
	SD	24.3
	Median	10.0
	Min	0
	Max	75
	Total missing	2

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 disease in your practice?	Less than 1 week	3 (18.8%)
	More than 1 week but less than 1 month	6 (37.5%)
	More than 1 month but less than 2 months	4 (25.0%)
	More than 2 months but less than 3 months	1 (6.3%)
	More than 3 months but less than 6 months	1 (6.3%)
	Other	1 (6.3%)
	Total Valid Response	16 (100.0%)
	Total missing	1

PT 4.4

Question	Response	Ophthalmologist
From the time a patient is screened, what is the average length of time he/she waits for diagnosis?	Less than 1 week	1 (6.3%)
	More than 1 month but less than 2 months	1 (6.3%)
	Don't know/Not sure	0 (0.0%)
	There is not wait, diagnosis is given when screened	14 (87.5%)
	Total Valid Response	16 (100.0%)
	Total missing	1

PT 4.5

Type of Treatment	Question	Response/time	Ophthalmologist
Laser photocoagulation	Is the treatment available?	Available within country	1 (6.3%)
		Available locally	1 (6.3%)
		Available in practice	13 (81.3%)
		Not available	1 (6.3%)
		Total valid response	16 (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)	13 (92.9%)
		Mean	1.8
		SD	1.4
		Median	1.0
		Min	0
		Max	4
		Don't know/not sure	1 (7.1%)
		Not applicable	
		Total valid response	14 (100.0%)

Type of Treatment	Question	Response/time	Ophthalmologist
	What is the average amount of time your patients wait for a first treatment?(weeks)	Total missing	3
		Total valid numeric response (n)	13 (92.9%)
		Mean	1.8
		SD	1.5
		Median	1.0
		Min	0
		Max	4
		Don't know/not sure	1 (7.1%)
		Total valid response	14 (100.0%)
		Total missing	3
	What is the average amount of time your patients wait for a second treatment?(weeks)	Total valid numeric response (n)	13 (86.7%)
		Mean	5.5
		SD	3.4
		Median	4.0
		Min	1
		Max	12
		Don't know/not sure	1 (6.7%)
		Not applicable	1 (6.7%)
		Total valid response	15 (100.0%)
		Total missing	2
Anti-VEGF therapies	Is the treatment available?	Available within country	1 (6.3%)
		Available locally	2 (12.5%)
		Available in practice	12 (75.0%)
		Not available	1 (6.3%)
		Total valid response	16 (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)	12 (85.7%)
		Mean	2.1
		SD	1.4
		Median	2.0
		Min	0
		Max	4
		Don't know/not sure	1 (7.1%)
		Not applicable	1 (7.1%)
		Total valid response	14 (100.0%)
		Total missing	3
	What is the average amount of time your patients wait for a first treatment?(weeks)	Total valid numeric response (n)	12 (85.7%)
		Mean	1.8
		SD	1.5
		Median	1.5
		Min	0
		Max	4
		Don't know/not sure	1 (7.1%)
		Not applicable	1 (7.1%)
		Total valid response	14 (100.0%)
		Total missing	3
	What is the average amount of time your patients wait for a second treatment?(weeks)	Total valid numeric response (n)	12 (80.0%)
		Mean	4.3
		SD	1.8
		Median	4.0
		Min	1
		Max	8
		Don't know/not	1 (6.7%)

Type of Treatment	Question	Response/time	Ophthalmologist
		sure	
		Not applicable	2 (13.3%)
		Total valid response	15 (100.0%)
		Total missing	2
Intravitreal steroid	Is the treatment available?	Available within country	2 (13.3%)
		Available locally	2 (13.3%)
		Available in practice	10 (66.7%)
		Not available	1 (6.7%)
		Total valid response	15 (100.0%)
		Total missing	2
	What is the average amount of time your patients wait for a consultation appointment? (weeks)	Total valid numeric response (n)	11 (91.7%)
		Mean	1.9
		SD	1.2
		Median	1.0
		Min	1
		Max	4
		Don't know/not sure	
		Not applicable	1 (8.3%)
		Total valid response	12 (100.0%)
		Total missing	5
	What is the average amount of time your patients wait for a first treatment?(weeks)	Total valid numeric response (n)	11 (84.6%)
		Mean	1.7
		SD	1.3
		Median	1.0
		Min	0
		Max	4
		Don't know/not	1 (7.7%)

Type of Treatment	Question	Response/time	Ophthalmologist
	What is the average amount of time your patients wait for a second treatment?(weeks)	sure	
		Not applicable	1 (7.7%)
		Total valid response	13 (100.0%)
		Total missing	4
		Total valid numeric response (n)	9 (64.3%)
		Mean	8.1
		SD	6.7
		Median	6.0
		Min	1
		Max	24
		Don't know/not sure	2 (14.3%)
		Not applicable	3 (21.4%)
		Total valid response	14 (100.0%)
		Total missing	3
Uncomplicated vitrectomy	Is the treatment available?	Available within country	1 (6.3%)
	What is the average amount of time your patients wait for a consultation appointment? (weeks)	Available locally	7 (43.8%)
		Available in practice	7 (43.8%)
		Not available	1 (6.3%)
		Total valid response	16 (100.0%)
		Total missing	1
		Total valid numeric response (n)	11 (78.6%)
		Mean	3.5
		SD	3.0
		Median	2.0
		Min	1
		Max	8
		Don't know/not	3 (21.4%)

Type of Treatment	Question	Response/time	Ophthalmologist
		sure	
		Not applicable	
		Total valid response	14 (100.0%)
		Total missing	3
	What is the average amount of time your patients wait for a first treatment?(weeks)	Total valid numeric response (n)	11 (78.6%)
		Mean	3.5
		SD	2.5
		Median	4.0
		Min	1
		Max	8
		Don't know/not sure	3 (21.4%)
		Total valid response	14 (100.0%)
		Total missing	3
	What is the average amount of time your patients wait for a second treatment?(weeks)	Total valid numeric response (n)	5 (33.3%)
		Mean	8.4
		SD	5.0
		Median	8.0
		Min	4
		Max	16
		Don't know/not sure	2 (13.3%)
		Not applicable	8 (53.3%)
		Total valid response	15 (100.0%)
		Total missing	2
Complex vitreo-retinal surgery	Is the treatment available?	Available within country	2 (12.5%)
		Available locally	7 (43.8%)
		Available in practice	5 (31.3%)

Type of Treatment	Question	Response/time	Ophthalmologist
		Not available	2 (12.5%)
		Total valid response	16 (100.0%)
		Total missing	1
	What is the average amount of time your patients wait for a consultation appointment? (weeks)	Total valid numeric response (n)	9 (69.2%)
		Mean	2.7
		SD	2.0
		Median	2.0
		Min	1
		Max	6
		Don't know/not sure	4 (30.8%)
		Not applicable	
		Total valid response	13 (100.0%)
		Total missing	4
	What is the average amount of time your patients wait for a first treatment?(weeks)	Total valid numeric response (n)	9 (69.2%)
		Mean	3.6
		SD	2.8
		Median	3.0
		Min	1
		Max	8
		Don't know/not sure	4 (30.8%)
		Total valid response	13 (100.0%)
		Total missing	4
	What is the average amount of time your patients wait for a second treatment?(weeks)	Total valid numeric response (n)	2 (14.3%)
		Mean	10.0
		SD	8.5
		Median	10.0

Type of Treatment	Question	Response/time	Ophthalmologist
		Min	4
		Max	16
		Don't know/not sure	5 (35.7%)
		Not applicable	7 (50.0%)
		Total valid response	14 (100.0%)
		Total missing	3

PT 4.6

Question	Response	Ophthalmologist
Do you personally administer treatment for diabetic retinopathy?	Yes	15 (93.8%)
	No	1 (6.3%)
	Total valid response	16 (100.0%)
	Total missing	1
Who administer it?	Refer to a provider at another facility	1 (100.0%)
	Total valid response	1 (100.0%)
	Total missing	16

PT 4.7

Question	Response	Ophthalmologist
Do any of the following influence how you treat diabetic retinopathy or diabetic macular edema?	Diabetes duration	5 (35.7%)
	Patient's age	3 (21.4%)
	Patient's gender	1 (7.1%)
	Presence of comorbidities such as hypertension, etc.	8 (57.1%)
	High glucose levels	7 (50.0%)
	Ability or inability to pay	4 (28.6%)
	Insurance restrictions	3 (21.4%)
	Patient educational level	4 (28.6%)
	Patient adherence to recommendations	3 (21.4%)

Question	Response	Ophthalmologist
	None of the above	2 (14.3%)
	Total valid response	14 (100.0%)
	Total missing	3

PT 4.8

Question	Response	Ophthalmologist
Do you treat diabetic retinopathy and diabetic macular edema based on:	Visual outcome	1 (6.7%)
	Both	13 (86.7%)
	Other	1 (6.7%)
	Total Valid Response	15 (100.0%)
	Total missing	2

PT 4.9

Question	Response	Ophthalmologist
How are your patients with diabetes screened for diabetic eye disease?	Fundoscopy undilated	1 (6.7%)
	Fundoscopy dilated	12 (80.0%)
	Retinal photo	5 (33.3%)
	Optical Coherence Tomography	5 (33.3%)
	Fluorescein Angiography	2 (13.3%)
	Total valid response	15 (100.0%)
	Total missing	2

PT 4.10

Question	Response	Ophthalmologist
In your opinion, do the majority of your patients present:	In time for screening	3 (20.0%)
	When visual problems have already occurred	11 (73.3%)
	Too late for effective treatment	1 (6.7%)
	Total Valid Response	15 (100.0%)
	Total missing	2

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	12 (75.0%)
	No	4 (25.0%)
	Total valid response	16 (100.0%)
	Total missing	1
If yes, When was your last training?	Don't know/Not sure	3 (25.0%)
	Five or more years ago	3 (25.0%)
	Greater than 1 year ago but less than 5 years	2 (16.7%)
	Within the past year	4 (33.3%)
	Total valid response	12 (100.0%)
	Total missing	5

PT 4.12

Question	Response	Ophthalmologist
Would you be interested in online education and certification on DME, Angiogenesis and Anti-VEGF therapies?	Yes	15 (93.8%)
	No	1 (6.3%)
	Total Valid Response	16 (100.0%)
	Total missing	1

PT 4.13

Question	Response	Ophthalmologist
How is outreach for screening for diabetic eye disease done in your main practice?	Health fairs for all	1 (6.3%)
	Health fairs for people with diabetes	3 (18.8%)
	Mobile screening centers	1 (6.3%)
	At vision centers	5 (31.3%)
	Other	1 (6.3%)
	Not done	7 (43.8%)

Question	Response	Ophthalmologist
	Total valid response	16 (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?	Reimbursement/restrictions on approved therapy	4 (25.0%)
	Late diagnosis	9 (56.3%)
	Referral pathways	11 (68.8%)
	Limited access to patient education on diabetic retinopathy and diabetic macular edema	7 (43.8%)
	No universal guidelines on referral/screening	6 (37.5%)
	No universal guidelines on how to treat	1 (6.3%)
	No universal guideline on when to treat	1 (6.3%)
	Current available therapies not effective	1 (6.3%)
	Government/insurance not able to cover patient costs	1 (6.3%)
	Multi-disciplinary team integration is poor	9 (56.3%)
	Ineffective screening services	6 (37.5%)
	Other	2 (12.5%)
	Total valid response	16 (100.0%)
	Total missing	1

EXP 1

Question	Response	Without DED (%)	With DED (%)	With DME (%)
Which of the following complications of diabetes do you have?	Cardiovascular disease/Stroke	3 (6.5%)	1 (12.5%)	0 (0.0%)
	Foot ulcers	2 (4.3%)	1 (12.5%)	0 (0.0%)
	Irritable bowel disease	7 (15.2%)	1 (12.5%)	0 (0.0%)
	Loss of feeling in hands or toes (neuropathy)	14 (30.4%)	3 (37.5%)	0 (0.0%)

Question	Response	Without DED (%)	With DED (%)	With DME (%)
	Vision loss	6 (13.0%)	6 (75.0%)	0 (0.0%)
	Amputation	1 (2.2%)	0 (0.0%)	0 (0.0%)
	Kidney disease	2 (4.3%)	0 (0.0%)	0 (0.0%)
	None	18 (39.1%)	0 (0.0%)	0 (0.0%)
	Don't know/Not sure	4 (8.7%)	0 (0.0%)	0 (0.0%)
	Total Valid Response	46 (100.0%)	8 (100.0%)	0 (0.0%)
	Total missing	16	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	13 (28.9%)	5 (71.4%)	0 (0.0%)
Impairment or health problem			
Diabetes	13 (81.3%)	5 (100.0%)	0 (0.0%)
Walking problem	9 (64.3%)	2 (50.0%)	0 (0.0%)
Hypertension/high blood pressure	6 (46.2%)	1 (25.0%)	0 (0.0%)
Fractures, bone/joint injury	5 (41.7%)	3 (100.0%)	0 (0.0%)
Back or neck problem	5 (38.5%)	4 (100.0%)	0 (0.0%)
Arthritis/rheumatism	4 (30.8%)	1 (25.0%)	0 (0.0%)
Mental or emotional health	4 (30.8%)	2 (40.0%)	0 (0.0%)
Lung/breathing problem	2 (13.3%)	0 (0.0%)	0 (0.0%)
Hearing problem	1 (7.1%)	1 (25.0%)	0 (0.0%)
Stroke problem	1 (7.1%)	1 (25.0%)	0 (0.0%)
Cancer	1 (7.1%)	1 (20.0%)	0 (0.0%)
Heart problem	1 (7.1%)	0 (0.0%)	0 (0.0%)
Eye/vision problem	0 (0.0%)	4 (80.0%)	0 (0.0%)

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

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

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

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

EXP 3

Health Status	Without DED (%)	With DED (%)	With DME (%)
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Health Status	Without DED (%)	With DED (%)	With DME (%)
Self-rated health: Good	19 (46.3%)	3 (60.0%)	0 (0.0%)
Self-rated health: Poor	22 (53.7%)	2 (40.0%)	0 (0.0%)
Physically unhealthy days	19 (51.4%)	2 (40.0%)	0 (0.0%)
Mentally unhealthy days	18 (50.0%)	2 (66.7%)	0 (0.0%)
Unhealthy days	27 (73.0%)	3 (100.0%)	0 (0.0%)
Activity limitation days	12 (42.9%)	2 (40.0%)	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 4

Item	Response	All respondents	Respondents with Type I diabetes	Respondents with Type II diabetes
How do you manage your diabetes?	Diet	47 (74.6%)	16 (80.0%)	23 (71.9%)
	Oral medicine	32 (50.8%)	4 (20.0%)	22 (68.8%)
	Exercise	27 (42.9%)	10 (50.0%)	13 (40.6%)
	Insulin	34 (54.0%)	19 (95.0%)	12 (37.5%)
	Natural/Herbal medicine	5 (7.9%)	2 (10.0%)	3 (9.4%)

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	25 (55.6%)	3 (37.5%)	0 (0.0%)
	Working without pay at home (e.g. housework, farming)	3 (6.7%)	0 (0.0%)	0 (0.0%)
	Volunteering	0 (0.0%)	2 (25.0%)	0 (0.0%)
	Retired	11 (24.4%)	3 (37.5%)	0 (0.0%)
	Student	2 (4.4%)	0 (0.0%)	0 (0.0%)
	Not working	4 (8.9%)	0 (0.0%)	0 (0.0%)
	Total Valid Response	45 (100.0%)	8 (100.0%)	0 (0.0%)
	Total missing	17	0	0
Do you receive assistance from	Medical assistance	1 (2.3%)	1 (16.7%)	0 (0.0%)

Item	Response	Without DED (%)	With DED (%)	With DME (%)
the government?				
	Pension assistance	12 (27.3%)	2 (33.3%)	0 (0.0%)
	None of the above	31 (70.5%)	4 (66.7%)	0 (0.0%)
	Total valid response	44 (100.0%)	6 (100.0%)	0
	Total missing	18	2	0
Did you have trouble paying for food at anytime during the past year?	Yes	15 (34.1%)	2 (40.0%)	0 (0.0%)
	No	29 (65.9%)	3 (60.0%)	0 (0.0%)
	Total Valid Response	44 (100.0%)	5 (100.0%)	0 (0.0%)
	Total missing	18	3	0

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

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

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

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

EXP 5.2: Age group 18-39 years

Item	Response	Without DED (%)	With DED (%)	With DME (%)
Are you currently working?	Working for pay	8 (72.7%)	2 (100.0%)	0 (0.0%)
	Working without pay at home (e.g. housework, farming)	1 (9.1%)	0 (0.0%)	0 (0.0%)
	Student	2 (18.2%)	0 (0.0%)	0 (0.0%)
	Total Valid Response	11 (100.0%)	2 (100.0%)	0 (0.0%)
	Total missing	7	0	0
Do you receive assistance from the government?	None of the above	10 (100.0%)	2 (100.0%)	0 (0.0%)
	Total valid response	10 (100.0%)	2 (100.0%)	0
	Total missing	8	0	0
Did you have trouble paying for food at anytime during the past year?	Yes	5 (45.5%)	2 (100.0%)	0 (0.0%)
	No	6 (54.5%)	0 (0.0%)	0 (0.0%)

Item	Response	Without DED (%)	With DED (%)	With DME (%)
	Total Valid Response	11 (100.0%)	2 (100.0%)	0 (0.0%)
	Total missing	7	0	0

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

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

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

EXP 5.3: Age group 40-59 years

Item	Response	Without DED (%)	With DED (%)	With DME (%)
Are you currently working?	Working for pay	15 (88.2%)	0 (0.0%)	0 (0.0%)
	Working without pay at home (e.g. housework, farming)	1 (5.9%)	0 (0.0%)	0 (0.0%)
	Retired	1 (5.9%)	0 (0.0%)	0 (0.0%)
	Total Valid Response	17 (100.0%)	0 (0.0%)	0 (0.0%)
	Total missing	6	0	0
Do you receive assistance from the government?	Medical assistance	1 (5.9%)	0 (0.0%)	0 (0.0%)
	None of the above	16 (94.1%)	0 (0.0%)	0 (0.0%)
	Total valid response	17 (100.0%)	0	0
	Total missing	6	0	0
Did you have trouble paying for food at anytime during the past year?	Yes	5 (29.4%)	0 (0.0%)	0 (0.0%)
	No	12 (70.6%)	0 (0.0%)	0 (0.0%)
	Total Valid Response	17 (100.0%)	0 (0.0%)	0 (0.0%)
	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 5.4: Age group 60-79 years

Item	Response	Without DED (%)	With DED (%)	With DME (%)
Are you currently working?	Working for pay	2 (12.5%)	1 (16.7%)	0 (0.0%)

Item	Response	Without DED (%)	With DED (%)	With DME (%)
	Working without pay at home (e.g. housework, farming)	1 (6.3%)	0 (0.0%)	0 (0.0%)
	Volunteering	0 (0.0%)	2 (33.3%)	0 (0.0%)
	Retired	9 (56.3%)	3 (50.0%)	0 (0.0%)
	Not working	4 (25.0%)	0 (0.0%)	0 (0.0%)
	Total Valid Response	16 (100.0%)	6 (100.0%)	0 (0.0%)
	Total missing	4	0	0
Do you receive assistance from the government?	Medical assistance	0 (0.0%)	1 (25.0%)	0 (0.0%)
	Pension assistance	12 (75.0%)	2 (50.0%)	0 (0.0%)
	None of the above	4 (25.0%)	2 (50.0%)	0 (0.0%)
	Total valid response	16 (100.0%)	4 (100.0%)	0
	Total missing	4	2	0
Did you have trouble paying for food at anytime during the past year?	Yes	5 (33.3%)	0 (0.0%)	0 (0.0%)
	No	10 (66.7%)	3 (100.0%)	0 (0.0%)
	Total Valid Response	15 (100.0%)	3 (100.0%)	0 (0.0%)
	Total missing	5	3	0

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

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

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

EXP 5.5: Age group 80+ years

Item	Response	Without DED (%)	With DED (%)	With DME (%)
Are you currently working?	Retired	1 (100.0%)	0 (0.0%)	0 (0.0%)
	Total Valid Response	1 (100.0%)	0 (0.0%)	0 (0.0%)
Do you receive assistance from the government?	None of the above	1 (100.0%)	0 (0.0%)	0 (0.0%)
	Total valid response	1 (100.0%)	0	0
	Total missing	0	0	0

Item	Response	Without DED (%)	With DED (%)	With DME (%)
Did you have trouble paying for food at anytime during the past year?	No	1 (100.0%)	0 (0.0%)	0 (0.0%)
	Total Valid Response	1 (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		70 (100%)	23 (32.9%)	35 (50.0%)	8 (11.4%)	0 (0.0%)
Gender	Male	9 (18.0%)	5 (55.6%)	4 (44.4%)	2 (22.2%)	0 (0.0%)
	Female	41 (82.0%)	10 (24.4%)	21 (51.2%)	5 (12.2%)	0 (0.0%)
	Total Missing	20	8	10	1	0
Age	18-39 yrs	20 (28.6%)	14 (70.0%)	3 (15.0%)	2 (10.0%)	0 (0.0%)
	40-59 yrs	23 (32.9%)	5 (21.7%)	17 (73.9%)	0 (0.0%)	0 (0.0%)
	60-79 yrs	26 (37.1%)	4 (15.4%)	14 (53.8%)	6 (23.1%)	0 (0.0%)
	80 yrs and over	1 (1.4%)	0 (0.0%)	1 (100.0%)	0 (0.0%)	0 (0.0%)
Time since diagnosis	Within the last year	2 (3.1%)	0 (0.0%)	1 (50.0%)	0 (0.0%)	0 (0.0%)
	1 - 5 years ago	19 (29.2%)	3 (15.8%)	11 (57.9%)	0 (0.0%)	0 (0.0%)
	6 - 10 years ago	13 (20.0%)	4 (30.8%)	9 (69.2%)	0 (0.0%)	0 (0.0%)
	11 - 15 years ago	11 (16.9%)	2 (18.2%)	5 (45.5%)	2 (18.2%)	0 (0.0%)
	16 - 20 years ago	5 (7.7%)	1 (20.0%)	3 (60.0%)	1 (20.0%)	0 (0.0%)
	21 years ago or longer	12 (18.5%)	11 (91.7%)	1 (8.3%)	5 (41.7%)	0 (0.0%)
	Don't know/Not sure	3 (4.6%)	0 (0.0%)	2 (66.7%)	0 (0.0%)	0 (0.0%)
	Total Missing	5	2	3	0	0
Control of Diabetes	Controlled	46 (78.0%)	13 (28.3%)	24 (52.2%)	8 (17.4%)	0 (0.0%)
	Not controlled	11 (18.6%)	3 (27.3%)	6 (54.5%)	0 (0.0%)	0 (0.0%)

Group	Subgroup	All respondents	Type 1 diabetes	Type 2 diabetes	With DED (%)	With DME (%)
	Don't know/Not sure	2 (3.4%)	0 (0.0%)	2 (100.0%)	0 (0.0%)	0 (0.0%)
	Total Missing	11	7	3	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	4 (50.0%)	0 (0.0%)
	No	2 (25.0%)	0 (0.0%)
	Don't know/Not sure	2 (25.0%)	0 (0.0%)
	Total valid response	8 (100.0%)	0 (0.0%)
What treatment did you receive?	Laser	4 (100.0%)	0 (0.0%)
	Anti-VEGF	3 (75.0%)	0 (0.0%)
	Surgery	2 (50.0%)	0 (0.0%)
	Total valid response	4 (100.0%)	0 (0.0%)
	Total missing	4	0
Did you complete the treatment?	Yes	4 (100.0%)	0 (0.0%)
	Total valid response	4 (100.0%)	0 (0.0%)
	Total missing	4	0
Do you feel that the treatment worked?	Yes, and vision improved	2 (50.0%)	0 (0.0%)
	Yes, but vision stayed the same	2 (50.0%)	0 (0.0%)
	Total valid response	4 (100.0%)	0 (0.0%)
	Total missing	4	0
What is/are the reason(s) that you did not complete the treatment?	Total valid response	0 (0.0%)	0 (0.0%)
	Total missing	8	0
What are the reason(s) that you have not had treatment for diabetic eye disease?	My doctor did not recommend any treatment	1 (50.0%)	0 (0.0%)
	Treatment would not be effective	1 (50.0%)	0 (0.0%)

Question	Response	With DED n (%)	With DME n (%)
	Total valid response	2 (100.0%)	0 (0.0%)
	Total missing	6	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.



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