

The Diabetic Retinopathy Barometer Report

## Germany











### **Contents**

Introduction: Global Study	3
Goal	3
Background	3
Study Populations	4
Introduction: Germany Study	5
Demographic Characteristics	Ę
Diabetes Profile	Ę
Study Populations: Germany	Ę
Germany DR Barometer Findings: Adults with Diabetes	8
Key Demographic Characteristics	8
Knowledge and Management of Diabetes	10
Nature and Information about Complications	11
Information about Diabetic Eye Disease and Diabetic Macular Edema	12
Screening for Diabetic Eye Disease	13
Treatment of Diabetic Eye Disease and Diabetic Macular Edema	14
Impact of Diabetic Eye Disease and Diabetic Macular Edema	16
Self-reported Quality of Life	18
Germany DR Barometer Findings: Health Care Professionals	19
Key Demographic Characteristics	19
Clinical Practice Characteristics	20
Patient Education Information	21
Guidelines and Protocols	22
Screening Protocols and Barriers in the Care Pathway	23
Germany DR Barometer Findings: Ophthalmologists	25
Screening	25
Treatment and Challenges	25
Germany DR Barometer Summary	27
References and Acknowledgement	29
Appendices	30



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 (DMF).

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

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, 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 DED, 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 contributions that they can make to family and community are not compromised.

#### **Background**

The DR Barometer study used a mix 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 eight countries: Germany, Saudi Arabia, Japan, Romania, Mexico, Argentina, Uganda, and Bangladesh. The countries were purposively selected for variation across income level and region, as delineated by the World Health Organization (WHO) and the World Bank Income Groups (WBIGs).

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

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

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

In the global analysis, respondents from each country were grouped into regions as defined by the WHO and into the WBIGs.

#### **Study Populations**

The people with diabetes who participated in the patient survey were self-selected, predominantly from patient organisations. Therefore, this population 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 principle should be applied when interpreting the results.

Even though the sample is not representative of the broader population of adults 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 people with diabetes and health care professionals around the world. This study provides a rich resource for generating unique insights into real-life experiences, 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



## Introduction **Germany Study**

### Demographic Characteristics<sup>1,2</sup>

Germany is the most populous country in the European Union with their current population at ~82 million ranking them 17th in the world. In the coming decades, Germany will experience a rapid increase in their ageing population.

In 2015, Germany had ~60% of its population between 14 and 59 years of age and 1 in 3 were aged 60 years and older. By 2050, people aged 14 to 59 years will decrease by over 10 % and there will be ~40 million people aged 60 years and older making up ~54% of Germany's population<sup>2</sup>.

Germany's ageing population will reflect an increase in the number of those aged 80 years and over which in 2015 was ~ 4 million (~5% of the population) to more than 10 million (14% of the population) in 2050<sup>2</sup>.

#### Diabetes Profile<sup>3</sup>

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

While the European region has the secondlowest age-adjusted comparative diabetes prevalence rate of any of the International Diabetes Federation (IDF) regions there are still many countries with relatively high diabetes prevalence rates.

Germany had the fourth-highest number of people with diabetes within the region (6.5[5.9-7.5‡] million) and its age-adjusted comparative prevalence stands at 7.4% comparative and 10.6% raw prevalence.

In 2015, there were over 6.5 million cases of diabetes in Germany with 55,059 diabetes-related deaths experienced and an estimated number of undiagnosed cases of 2,498,000.

Germany's high number of people with diabetes is exemplified by being placed third in the world for diabetes-related health expenditures with an estimated spend of 35 billion USD which is predicted to increase to 36 billion USD by 2040.

#### **Study Populations: Germany**

As reported by 290 adults with diabetes in Germany, 21% of respondents have been diagnosed with DED and a further 14% with DME.

Seventy-five health care professionals completed the survey in Germany. Of these, 39 were diabetes specialist providers (52%), ten were ophthalmologists (13%), and seven were primary care providers (9.3%). The remaining respondents were optometrists, nurses, health educators or other types of professionals.

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

The DR Barometer study was conducted in 41 countries. In Germany, 290 adults with diabetes and 75 health care professionals provided new information about the experiences of living with, managing and treating diabetes, DR and DME.

50%

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



34%

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

**DR:** Diabetic Retinopathy

DME: Diabetic Macular Edema

DRBarometer.com











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











85%

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



33%

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



77%

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

29%

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





## Germany DR Barometer Findings:

#### **Adults with Diabetes**

### Key Demographic Characteristics

Two hundred and ninety adults with diabetes completed the patients' survey in Germany: 51% were females and 49% were male. Seventy-two percent lived in an urban setting and 28% resided in a non-urban setting (see Appendix Table 4.2).

The education levels of all respondents was as follows: 1.2% did not complete primary school level, 54% were educated to a primary school level, 11% to a secondary school level, 29% to a college or university level, and 4% with a graduate or post-graduate level (see Appendix Table 4.3). Forty-five percent of all respondents were working for pay, 38% were retired, and 7.7% stated they were not working (see Appendix Table 4.4).

Most respondents (73%) were aged between 40 and 79 years (36% were 40-59 years and 37% were 60-79 years). Sixty percent were of traditional working age (18-59 years) (see Table 1).

Of the respondents in Germany, 59% had been diagnosed with type 1 diabetes and 39% with type 2 diabetes. A further 1.7% of respondents were either unsure or did not know their type of diabetes (see Appendix Table 2.1).

Forty-six percent of the adults with diabetes were diagnosed with diabetes 21 years ago or more. Five percent of respondents were diagnosed with diabetes within the last year, 1 - 5 years ago (15%), 6 - 10 years ago (11%), 11 - 15 years ago (13%), and 16 - 20 years (8.1%) (see Appendix table 2.2).

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

Amongst 18 to 39-year-olds, 81% had type 1 and 17% had type 2 diabetes. In the 40-59 year age group, 68% had type 1 and 31% had type 2 diabetes, 42% of 60-79-year-olds had type 1 diabetes and 56% had type 2.

Twenty-one percent of respondents (n=62) reported they have been diagnosed with DED and a further 14% (n=40) with DME. In the 18-39 year age group, 15% had DED and 5.8% had DME. For the 40-59 year age group, 27% had DED and 11% had DME, in the 60-79 year age group, 22% had DED and 20% had DME.

A particularly important trend noted in the findings was that the longer the time since diabetes was diagnosed, the greater the likelihood for DED and DME to be detected.

Those in the first five years since diagnosis of diabetes, 4.5% of respondents were diagnosed with DED and 6.8% with DME. This increased to 8.1% of respondents for both diseases 11-15 years since diagnosis. The proportion with DED substantially increased to 17% (16-20 years since diagnosis) and further to 39% of respondents diagnosed more than 21 years. Of note is the finding that over one in five respondents (23%) diagnosed more than 21 years had DME.

While most (84%) respondents reported that their diabetes was well controlled, 15% felt that their diabetes was not well controlled. For those whose diabetes was controlled, 20% had DED and 16% had DME. In those whose diabetes was not controlled 42% had DED and 11% had DME.



Table 1: Summary of key characteristics of adults with diabetes

All respondents         290 (100%)         172 (59.3%)         113 (39.0%)         62 (21.4%)         40 (13.8%)           Gender         Male         121 (48.6%)         60 (49.6%)         60 (49.6%)         32 (26.4%)         22 (18.2%)           Female         128 (51.4%)         93 (72.7%)         33 (25.8%)         29 (22.7%)         18 (14.1%)           Age         18-39 yrs.         69 (23.8%)         56 (81.2%)         12 (17.4%)         10 (14.5%)         4 (5.8%)           40-59 yrs.         104 (35.9%)         71 (68.3%)         32 (30.8%)         28 (26.9%)         11 (10.6%)           60-79 yrs.         107 (36.9%)         45 (42.1%)         60 (56.1%)         23 (21.5%)         21 (19.6%)           Time since diagnosis         Within the last year         13 (4.6%)         1 (7.7%)         11 (84.6%)         1 (7.7%)         0 (0.0%)           Time since diagnosis         Within the last year         13 (4.6%)         1 (7.7%)         11 (84.6%)         1 (7.7%)         0 (0.0%)           1 - 5 yrs.         44 (15.4%)         16 (36.4%)         26 (59.1%)         2 (4.5%)         3 (6.8%)           6 - 10 yrs.         32 (11.2%)         11 (34.4%)         21 (55.6%)         1 (3.1%)         2 (6.3%)           11 - 15 yrs.         37 (	Group	Subgroup	All Respondents	Type 1 diabetes	Type 2 diabetes	With DED	With DME
Female         128 [51.4%]         93 [72.7%]         33 [25.8%]         29 [22.7%]         18 [14.1%]           Age         18-39 yrs.         69 [23.8%]         56 [81.2%]         12 [17.4%]         10 [14.5%]         4 [5.8%]           40-59 yrs.         104 [35.9%]         71 [68.3%]         32 [30.8%]         28 [26.9%]         11 [10.6%]           60-79 yrs.         107 [36.9%]         45 [42.1%]         60 [56.1%]         23 [21.5%]         21 [19.6%]           Time since diagnosis         Within the last year         13 [4.6%]         1 (7.7%]         11 [84.6%]         1 (7.7%]         0 [0.0%]           Time since diagnosis         Within the last year         13 [4.6%]         1 (7.7%]         11 [84.6%]         1 (7.7%]         0 [0.0%]           Time since diagnosis         Within the last year         13 [4.6%]         1 (7.7%]         11 [84.6%]         1 (7.7%]         0 [0.0%]           Time since diagnosis         Within the last year         13 [4.6%]         1 (7.7%]         11 [84.6%]         1 (7.7%]         0 [0.0%]           Time since diagnosis         Within the last year         13 [4.6%]         1 (7.7%]         11 [84.6%]         1 (7.7%]         0 (0.0%]           Time since diagnosis         20 [20.28]         12 [20.28]         2 (20.5%)			290 (100%)	172 (59.3%)	113 (39.0%)	62 (21.4%)	40 (13.8%)
Age         18-39 yrs.         69 [23.8%]         56 [81.2%]         12 [17.4%]         10 [14.5%]         4 [5.8%]           40-59 yrs.         104 [35.9%]         71 [68.3%]         32 [30.8%]         28 [26.9%]         11 [10.6%]           60-79 yrs.         107 [36.9%]         45 [42.1%]         60 [56.1%]         23 [21.5%]         21 [19.6%]           Time since diagnosis           Within the last year         13 [4.6%]         1 [7.7%]         11 [84.6%]         1 [7.7%]         0 [0.0%]           1 - 5 yrs.         44 [15.4%]         16 [36.4%]         26 [59.1%]         2 [4.5%]         3 [6.8%]           6 - 10 yrs.         32 [11.2%]         11 [34.4%]         21 [65.6%]         1 [3.1%]         2 [6.3%]           11 - 15 yrs.         37 [13.0%]         17 [45.9%]         19 [51.4%]         3 [8.1%]         3 [8.1%]           16 - 20 yrs.         23 [8.1%]         13 [56.5%]         10 [43.5%]         4 [17.4%]         2 [8.7%]           Don't know/ Not sure         4 [1.4%]         1 [25.0%]         2 [50.0%]         0 [0.0%]         0 [0.0%]           Control of Diabetes         Not controlled         38 [14.3%]         24 [63.2%]         13 [34.2%]         44 [20.0%]         34 [15.5%]	Gender	Male	121 (48.6%)	60 (49.6%)	60 (49.6%)	32 (26.4%)	22 (18.2%)
Age       18-39 yrs.       69 [23.8%]       56 [81.2%]       12 [17.4%]       10 [14.5%]       4 [5.8%]         40-59 yrs.       104 [35.9%]       71 [68.3%]       32 [30.8%]       28 [26.9%]       11 [10.6%]         60-79 yrs.       107 [36.9%]       45 [42.1%]       60 [56.1%]       23 [21.5%]       21 [19.6%]         Time since diagnosis       Within the last year       13 [4.6%]       1 [7.7%]       11 [84.6%]       1 [7.7%]       0 [0.0%]         1 - 5 yrs.       44 [15.4%]       16 [36.4%]       26 [59.1%]       2 [4.5%]       3 [6.8%]         6 - 10 yrs.       32 [11.2%]       11 [34.4%]       21 [65.6%]       1 [3.1%]       2 [6.3%]         11 - 15 yrs.       37 [13.0%]       17 [45.9%]       19 [51.4%]       3 [8.1%]       3 [8.1%]         16 - 20 yrs.       23 [8.1%]       13 [56.5%]       10 [43.5%]       4 [17.4%]       2 [8.7%]         21 yrs. plus       132 [46.3%]       110 [83.3%]       22 [16.7%]       51 [38.6%]       30 [22.7%]         Don't know/Not sure       4 [1.4%]       1 [25.0%]       84 [38.2%]       44 [20.0%]       34 [15.5%]         Controlled       220 [83.0%]       134 [60.9%]       84 [38.2%]       44 [20.0%]       34 [15.5%]		Female	128 (51.4%)	93 (72.7%)	33 (25.8%)	29 (22.7%)	18 (14.1%)
40-59 yrs.       104 [35.9%]       71 [68.3%]       32 [30.8%]       28 [26.9%]       11 [10.6%]         60-79 yrs.       107 [36.9%]       45 [42.1%]       60 [56.1%]       23 [21.5%]       21 [19.6%]         Time since diagnosis       Within the last year       13 [4.6%]       1 [7.7%]       11 [84.6%]       1 [7.7%]       0 [0.0%]         1 - 5 yrs.       44 [15.4%]       16 [36.4%]       26 [59.1%]       2 [4.5%]       3 [6.8%]         6 - 10 yrs.       32 [11.2%]       11 [34.4%]       21 [65.6%]       1 [3.1%]       2 [6.3%]         11 - 15 yrs.       37 [13.0%]       17 [45.9%]       19 [51.4%]       3 [8.1%]       3 [8.1%]         16 - 20 yrs.       23 [8.1%]       13 [56.5%]       10 [43.5%]       4 [17.4%]       2 [8.7%]         21 yrs. plus       132 [46.3%]       110 [83.3%]       22 [16.7%]       51 [38.6%]       30 [22.7%]         Don't know/ Not sure       4 [1.4%]       1 [25.0%]       2 [50.0%]       0 [0.0%]       0 [0.0%]         Controlled       220 [83.0%]       134 [60.9%]       84 [38.2%]       44 [20.0%]       34 [15.5%]         Not controlled       38 [14.3%]       24 [63.2%]       13 [34.2%]       16 [42.1%]       4 [10.5%]		Total Missing	41	19	20	1	0
60-79 yrs.       107 (36.9%)       45 (42.1%)       60 (56.1%)       23 (21.5%)       21 (19.6%)         Time since diagnosis       Within the last year       13 (4.6%)       1 (7.7%)       11 (84.6%)       1 (7.7%)       0 (0.0%)         1 - 5 yrs.       44 (15.4%)       16 (36.4%)       26 (59.1%)       2 (4.5%)       3 (6.8%)         6 - 10 yrs.       32 (11.2%)       11 (34.4%)       21 (65.6%)       1 (3.1%)       2 (6.3%)         11 - 15 yrs.       37 (13.0%)       17 (45.9%)       19 (51.4%)       3 (8.1%)       3 (8.1%)         16 - 20 yrs.       23 (8.1%)       13 (56.5%)       10 (43.5%)       4 (17.4%)       2 (8.7%)         21 yrs. plus       132 (46.3%)       110 (83.3%)       22 (16.7%)       51 (38.6%)       30 (22.7%)         Don't know/ Not sure       4 (1.4%)       1 (25.0%)       2 (50.0%)       0 (0.0%)       0 (0.0%)         Control of Diabetes       Controlled       220 (83.0%)       134 (60.9%)       84 (38.2%)       44 (20.0%)       34 (15.5%)         Don't know/ Not controlled       38 (14.3%)       24 (63.2%)       13 (34.2%)       16 (42.1%)       4 (10.5%)	Age	18-39 yrs.	69 (23.8%)	56 (81.2%)	12 (17.4%)	10 (14.5%)	4 (5.8%)
Time since diagnosis         Within the last year         13 (4.6%)         1 (7.7%)         11 (84.6%)         1 (7.7%)         0 (0.0%)           1 - 5 yrs.         44 (15.4%)         16 (36.4%)         26 (59.1%)         2 (4.5%)         3 (6.8%)           6 - 10 yrs.         32 (11.2%)         11 (34.4%)         21 (65.6%)         1 (3.1%)         2 (6.3%)           11 - 15 yrs.         37 (13.0%)         17 (45.9%)         19 (51.4%)         3 (8.1%)         3 (8.1%)           16 - 20 yrs.         23 (8.1%)         13 (56.5%)         10 (43.5%)         4 (17.4%)         2 (8.7%)           21 yrs. plus         132 (46.3%)         110 (83.3%)         22 (16.7%)         51 (38.6%)         30 (22.7%)           Don't know/ Not sure         4 (1.4%)         1 (25.0%)         2 (50.0%)         0 (0.0%)         0 (0.0%)           Control of Diabetes         Controlled         220 (83.0%)         134 (60.9%)         84 (38.2%)         44 (20.0%)         34 (15.5%)		40-59 yrs.	104 (35.9%)	71 (68.3%)	32 (30.8%)	28 (26.9%)	11 (10.6%)
Time since diagnosis         Within the last year         13 [4.6%]         1 [7.7%]         11 [84.6%]         1 [7.7%]         0 [0.0%]           1 - 5 yrs.         44 [15.4%]         16 [36.4%]         26 [59.1%]         2 [4.5%]         3 [6.8%]           6 - 10 yrs.         32 [11.2%]         11 [34.4%]         21 [65.6%]         1 [3.1%]         2 [6.3%]           11 - 15 yrs.         37 [13.0%]         17 [45.9%]         19 [51.4%]         3 [8.1%]         3 [8.1%]           16 - 20 yrs.         23 [8.1%]         13 [56.5%]         10 [43.5%]         4 [17.4%]         2 [8.7%]           21 yrs. plus         132 [46.3%]         110 [83.3%]         22 [16.7%]         51 [38.6%]         30 [22.7%]           Don't know/ Not sure         4 [1.4%]         1 [25.0%]         2 [50.0%]         0 [0.0%]         0 [0.0%]           Control of Diabetes         Controlled         220 [83.0%]         134 [60.9%]         84 [38.2%]         44 [20.0%]         34 [15.5%]		60-79 yrs.	107 (36.9%)	45 (42.1%)	60 (56.1%)	23 (21.5%)	21 (19.6%)
diagnosis         year         13 (4.8%)         1 (7.7%)         11 (84.8%)         1 (7.7%)         0 (0.0%)           1 - 5 yrs.         44 (15.4%)         16 (36.4%)         26 (59.1%)         2 (4.5%)         3 (6.8%)           6 - 10 yrs.         32 (11.2%)         11 (34.4%)         21 (65.6%)         1 (3.1%)         2 (6.3%)           11 - 15 yrs.         37 (13.0%)         17 (45.9%)         19 (51.4%)         3 (8.1%)         3 (8.1%)           16 - 20 yrs.         23 (8.1%)         13 (56.5%)         10 (43.5%)         4 (17.4%)         2 (8.7%)           21 yrs. plus         132 (46.3%)         110 (83.3%)         22 (16.7%)         51 (38.6%)         30 (22.7%)           Don't know/ Not sure         4 (1.4%)         1 (25.0%)         2 (50.0%)         0 (0.0%)         0 (0.0%)           Control of Diabetes         Controlled         220 (83.0%)         134 (60.9%)         84 (38.2%)         44 (20.0%)         34 (15.5%)           Don't know/ Not controlled         38 (14.3%)         24 (63.2%)         13 (34.2%)         16 (42.1%)         4 (10.5%)			10 (3.4%)	0 (0.0%)	9 (90.0%)	1 (10.0%)	4 (40.0%)
6 - 10 yrs. 32 (11.2%) 11 (34.4%) 21 (65.6%) 1 (3.1%) 2 (6.3%)  11 - 15 yrs. 37 (13.0%) 17 (45.9%) 19 (51.4%) 3 (8.1%) 3 (8.1%)  16 - 20 yrs. 23 (8.1%) 13 (56.5%) 10 (43.5%) 4 (17.4%) 2 (8.7%)  21 yrs. plus 132 (46.3%) 110 (83.3%) 22 (16.7%) 51 (38.6%) 30 (22.7%)  Don't know/ Not sure 4 (1.4%) 1 (25.0%) 2 (50.0%) 0 (0.0%) 0 (0.0%)  Total Missing 5 3 2 0 0  Control of Diabetes  Controlled 220 (83.0%) 134 (60.9%) 84 (38.2%) 44 (20.0%) 34 (15.5%)  Not controlled 38 (14.3%) 24 (63.2%) 13 (34.2%) 16 (42.1%) 4 (10.5%)			13 (4.6%)	1 (7.7%)	11 (84.6%)	1 (7.7%)	0 (0.0%)
11 - 15 yrs. 37 (13.0%) 17 (45.9%) 19 (51.4%) 3 (8.1%) 3 (8.1%) 16 - 20 yrs. 23 (8.1%) 13 (56.5%) 10 (43.5%) 4 (17.4%) 2 (8.7%) 21 yrs. plus 132 (46.3%) 110 (83.3%) 22 (16.7%) 51 (38.6%) 30 (22.7%)  Don't know/ Not sure 4 (1.4%) 1 (25.0%) 2 (50.0%) 0 (0.0%) 0 (0.0%)  Total Missing 5 3 2 0 0  Control of Diabetes  Controlled 220 (83.0%) 134 (60.9%) 84 (38.2%) 44 (20.0%) 34 (15.5%)  Not controlled 38 (14.3%) 24 (63.2%) 13 (34.2%) 16 (42.1%) 4 (10.5%)		1 - 5 yrs.	44 (15.4%)	16 (36.4%)	26 (59.1%)	2 (4.5%)	3 (6.8%)
16 - 20 yrs.       23 (8.1%)       13 (56.5%)       10 (43.5%)       4 (17.4%)       2 (8.7%)         21 yrs. plus       132 (46.3%)       110 (83.3%)       22 (16.7%)       51 (38.6%)       30 (22.7%)         Don't know/ Not sure       4 (1.4%)       1 (25.0%)       2 (50.0%)       0 (0.0%)       0 (0.0%)         Total Missing       5       3       2       0       0         Control of Diabetes       Controlled       220 (83.0%)       134 (60.9%)       84 (38.2%)       44 (20.0%)       34 (15.5%)         Not controlled       38 (14.3%)       24 (63.2%)       13 (34.2%)       16 (42.1%)       4 (10.5%)		6 - 10 yrs.	32 (11.2%)	11 (34.4%)	21 (65.6%)	1 (3.1%)	2 (6.3%)
21 yrs. plus 132 (46.3%) 110 (83.3%) 22 (16.7%) 51 (38.6%) 30 (22.7%)  Don't know/ Not sure 4 (1.4%) 1 (25.0%) 2 (50.0%) 0 (0.0%) 0 (0.0%)  Total Missing 5 3 2 0 0  Control of Diabetes Controlled 220 (83.0%) 134 (60.9%) 84 (38.2%) 44 (20.0%) 34 (15.5%)  Not controlled 38 (14.3%) 24 (63.2%) 13 (34.2%) 16 (42.1%) 4 (10.5%)		11 - 15 yrs.	37 (13.0%)	17 (45.9%)	19 (51.4%)	3 (8.1%)	3 (8.1%)
Don't know/ Not sure		16 - 20 yrs.	23 (8.1%)	13 (56.5%)	10 (43.5%)	4 (17.4%)	2 (8.7%)
Not sure 4 (1.4%) 1 (25.0%) 2 (50.0%) 0 (0.0%) 0 (0.0%)  Total Missing 5 3 2 0 0  Control of Diabetes Controlled 220 (83.0%) 134 (60.9%) 84 (38.2%) 44 (20.0%) 34 (15.5%)  Not controlled 38 (14.3%) 24 (63.2%) 13 (34.2%) 16 (42.1%) 4 (10.5%)		21 yrs. plus	132 (46.3%)	110 (83.3%)	22 (16.7%)	51 (38.6%)	30 (22.7%)
Control of Diabetes         Controlled         220 [83.0%]         134 [60.9%]         84 [38.2%]         44 [20.0%]         34 [15.5%]           Not controlled         38 [14.3%]         24 [63.2%]         13 [34.2%]         16 [42.1%]         4 [10.5%]			4 [1.4%]	1 (25.0%)	2 (50.0%)	0 (0.0%)	0 (0.0%)
Diabetes         Controlled         220 [83.0%]         134 [60.9%]         84 [38.2%]         44 [20.0%]         34 [15.5%]           Not controlled         38 [14.3%]         24 [63.2%]         13 [34.2%]         16 [42.1%]         4 [10.5%]		Total Missing	5	3	2	0	0
Don't know/		Controlled	220 (83.0%)	134 (60.9%)	84 (38.2%)	44 (20.0%)	34 (15.5%)
Don't know/ 7 (2.49/) 2 (20.49/) 4 (57.19/) 1 (14.29/) 2 (20.49/)		Not controlled	38 (14.3%)	24 (63.2%)	13 (34.2%)	16 (42.1%)	4 (10.5%)
Not sure / (2.6%) 2 (28.6%) 4 (57.1%) 1 (14.3%) 2 (28.6%)			7 (2.6%)	2 (28.6%)	4 (57.1%)	1 (14.3%)	2 (28.6%)
Total Missing 25 12 12 1 0		Total Missing	25	12	12	1	0

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

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

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

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

### **Knowledge and Management of Diabetes**

Ninety-eight percent of those surveyed saw a health care professional for their diabetes, with 70% seeing a diabetes specialist (average number of visits was 4.7 times per year) and 28% seeing a general/family doctor (average number of visits was 4.7 times per year) (see Appendix Table 2.3.1 and 2.3.2).

Adults with diabetes were informed about their condition through a variety of channels. Seventy-six percent received information from a doctor or nurse, 59% from a health educator, and 47% from the internet (see Table 2 and Appendix Table 2.4).

Table 2: Source of information regarding diabetes

Information Source	All Respondents (n=278)
Doctor or nurse	212 (76.3%)
Health educator	164 (59.0%)
Internet	130 (46.8%)
Diabetes organisation or other health organisation	89 (32.0%)
TV/Radio/Newspaper/Magazines	64 (23.0%)
Nutritionist or dietician	59 (21.2%)
Family/Friends/Neighbours	42 (15.1%)
Social media (e.g. Facebook, Twitter, blogs)	33 (11.9%)
Pharmacist	19 (6.8%)
Other	20 (7.2%)
None of the above	5 (1.8%)

A range of strategies was used by respondents to manage their diabetes. For those with type 1 diabetes, apart from insulin, 30% managed their diabetes with diet, and 25% with exercise. Of the respondents with type 2 diabetes, 77% managed their condition with diet, 73% with oral medicine, 52% with exercise, and 47% with insulin.

Sixty-four percent of respondents were enrolled in diabetes management programmes. Eighty-four percent of those said the programme included education on the importance of screening for diabetic eye complications (see Appendix Table 2.6).

The nature and frequency of tests that people with diabetes experienced included blood glucose checks and undilated eye checks. Of the respondents that had eye checks (96%), these occurred at the following intervals: less than 6 months (61%), 6 - 12 months (25%), and greater than 12 months (7.1%) (see Appendix Table 2.7).

Eighty-three percent of all respondents thought their diabetes was controlled (32% very well controlled and 51% well controlled). Fourteen percent thought their diabetes was not well controlled (see Appendix Table 2.8).

The main challenges in controlling diabetes cited by respondents were: it was too hard to eat the right things (30%), the high cost of care (26%), there were long wait times for an appointment to see the doctor or specialist (20%), and there were too many other things to do (19%) (see Appendix Table 2.9).

Free or low cost medicines or monitoring materials (44%), support from family or friends (43%), and health education and information (36%) were identified as important to improving the management of a person's diabetes. Sixteen percent of respondents stated that none of the services listed helped them to better manage their diabetes (see Appendix Table 2.10).



### Nature and Information about Complications

Ninety-four percent of respondents were aware of vision loss and other complications such as: neuropathy (88%), amputation (86%), kidney disease (86%), and cardiovascular disease or stroke (78%) associated with diabetes (see Appendix Table 2.11).

Respondents were most concerned about: vision loss (51%), cardiovascular disease or stroke (19%), kidney disease (14%), amputation (5.7%), and neuropathy (2.3%) (see Appendix Table 2.12).

Forty-six percent of respondents reported that they have no complications of diabetes. However, of those who did report complications: 26% had vision loss, neuropathy (22%), cardiovascular disease or stroke (15%), kidney disease (6.5%), and foot ulcers (1.5%) (see Figure 1 and Appendix Table 2.13).

Aside from vision loss, there was a considerable increase in the frequency of people with DED and DME experiencing complications compared with people without DED. The frequency of neuropathy increased from 10% in those without DED to 38% in DED and 48% in DME. Likewise. the frequency of cardiovascular disease increased from 10% in people without DED to 27% in those with DED and to 18% with DME. The frequency of other complications also increased, but the number of respondents was small. This emphasises how other complications develop alongside the development of DED and DME and thus the additional health burdens of people with DED or DME (see Table 3 and Appendix EXP 1).

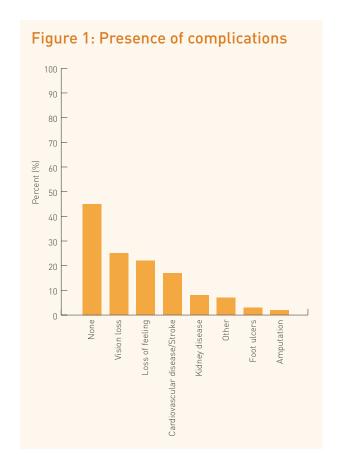


Table 3: Presence of complications without DED, with DED or DME

Complication	Without DED (n=159)	With DED (n=60)	With DME (n=40)
Any	56 (35.2%)	48 (80.0%)	37 (92.5%)
Vision loss	13 (8.2%)	31 (51.7%)	24 (60.0%)
Loss of feeling in hands or toes (neuropathy)	16 (10.1%)	23 (38.3%)	19 (47.5%)
Cardiovascular disease/Stroke	16 (10.1%)	16 (26.7%)	7 (17.5%)
Kidney disease	6 (3.8%)	5 (8.3%)	6 (15.0%)
Amputation	1 (0.6%)	1 (1.7%)	1 (2.5%)
Foot ulcers	2 (1.3%)	1 (1.7%)	1 (2.5%)
Other	7 (4.4%)	7 (11.7%)	2 (5.0%)
None	103 (64.8%)	12 (20.0%)	3 (7.5%)

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".

 $\ensuremath{\mathsf{NB}}$  [4]: Percentages within groups are calculated from non-missing data for that question.

NB [5]: Not all responses have been presented in this table, but have been included under 'Any'. Please see Appendix Table EXP012 for the full list of responses.

#### Information about Diabetic Eye Disease and Diabetic Macular Edema

While eighty-six percent of respondents stated that eye complications were discussed with their health care professional, more than a quarter (29%) either never discussed eye complications with their doctor (13%) or did so only after the onset of symptoms (16%). The frequency of the regular discussions varied from every visit (20%), multiple times a year (24%), and once a year (25%) (see Appendix Table 2.14).

Ninety-three percent of respondents said that they do what they can to prevent vision problems (e.g. get routine screenings, visit specialists), yet myths and perceptions around vision changes and prevention were evident with 5.3% who thought that vision

problems were a normal part of ageing and 5.8% making no special effort to prevent vision problems (see Appendix Table 2.15).

Seventy-nine percent of all respondents received information about DR and DME with the doctor or nurse being the most common source (50%) followed by the internet (36%) and diabetes, or other health, organisation (24%). A surprise finding was that one in five respondents did not receive such information from any of the sources listed (see Table 4 and Appendix 3.94).

Seventy-seven percent of respondents with DED and 90% of respondents with DME received in formation. Doctors or nurses were the most common source of information reported by 58% of people with DED and 75% of those with DME (see Table 4 and Appendix EXP 8).

Table 4: Source of information about DR and DME

Source	All respondents (n=234)	With DED (n=52)	With DME (n=40)
Doctor/ Nurse	118 (50.4%)	30 (57.7%)	30 (75.0%)
Internet	84 (35.9%)	19 (36.5%)	14 (35.0%)
Diabetes organisation or other health organisation	55 (23.5%)	13 (25.0%)	8 (20.0%)
TV/Radio/ Newspaper/ Magazines	39 (16.7%)	4 (7.7%)	3 (7.5%)
Health educator	16 (6.8%)	1 (1.9%)	3 (7.5%)
Family/ Friends/ Neighbours	6 (2.6%)	1 (1.9%)	0 (0.0%)
Other	11 (4.7%)	1 (1.9%)	2 (5.0%)
None of the above	50 (21.4%)	12 (23.1%)	4 (10.0%)

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

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

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



### Screening for Diabetic Eye Disease

Ninety-four percent of the respondents reported having an eye exam for DED, with 88% reporting to have had an eye exam within the last year, and a further 7.6% more than one year ago but less than two years ago. Seventy-three percent of respondents were aware of a government sponsored screening programme for DED (see Appendix Table 3.1 and 3.2).

Ninety-seven percent of those surveyed thought they should have their eyes examined for DED once a year, two said that testing should only happen when symptoms occur, one respondent thought they should be tested every two years, and two said that testing should not occur at all (see Appendix Table 3.4).

The biggest barriers to eye exams were: there were long wait times for an appointment (50%), the long wait times on the day of the visit (43%), and a general fear of treatment or the results (22%) (see Table 5 and Appendix Table 3.5).

Table 5: Barriers to eye examinations

Identified Barriers	All Respondents (n=205)
Long wait time for appointment	103 (50.2%)
Long wait time on the day of the visit	89 (43.4%)
Fear of treatment/results	45 (22.0%)
They are expensive	24 (11.7%)
Burden on my family/friends	17 (8.3%)
Too many other things to do or worry about	16 (7.8%)
Don't know much about my condition	13 (6.3%)
Limited access to diabetes specialists	12 (5.9%)
Recommended treatments for eye problems are not available	11 (5.4%)
Eye exams are not available near my home	10 (4.9%)
Referral process is complicated or takes too long	6 (2.9%)
I'm not likely to have eye complications	4 (2.0%)
Eye exams are not important	4 (2.0%)
Clinics are too small or lack necessary equipment/staff	4 (2.0%)
Other	33 (16.1%)

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

Treatment was assessed separately in people with DED and in those with DME. For those with DED 73% (n=45) had received treatment and the most common treatments were laser treatment (84%) and surgery (42%). Of those who received treatment, 73% (n=33) completed their treatment and 22% (n=10) were currently still receiving treatment. Sixty-two percent felt that treatment had been successful and either their vision had improved (14%) or vision had stayed the same (48%). Thirty-nine percent felt that the treatment did not work (see Table 6 and Appendix EXP 7).

For the sixteen respondents with DED who had not received treatment, the most common reason reported was that their doctor did not recommend any treatment (69%).

Eighty-seven percent of respondents with DME (n=32) had received treatment and the most common treatments were laser (91%) and anti-VEGF therapy (53%). Sixty percent felt that treatment had been successful and either their vision had improved (23%) or vision had stayed the same (37%). Twenty-three percent felt that the treatment did not work.

The majority (85%) of people with DME said they would prefer proactive treatment to prevent further vision loss rather than reactive treatment once further vision loss occurred (7.7%) (see Appendix Table 3.8).



Table 6: Treatment characteristics of patients with DED and DME

Question	Response	With DED (n=62)	With DME (n=40)
Have you had any treatment for diabetic eye disease?	Yes	45 (72.6%)	32 (86.5%)
	No	16 (25.8%)	4 (10.8%)
	Don't know/Not sure	1 (1.6%)	1 (2.7%)
What treatment did you receive?	Laser	38 (84.4%)	29 (90.6%)
	Anti-VEGF	7 (15.6%)	17 (53.1%)
	Surgery	19 (42.2%)	12 (37.5%)
	Other	9 (20.0%)	1 (3.1%)
Did you complete the treatment?	Yes	33 (73.3%)	15 (46.9%)
	No	1 (2.2%)	2 (6.3%)
	Still receiving treatment	10 (22.2%)	15 (46.9%)
	Don't know/Not sure	1 (2.2%)	0 (0.0%)
Do you feel that the treatment worked?	Yes, and vision improved	6 (13.6%)	7 (23.3%)
	Yes, but vision stayed the same	21 [47.7%]	11 (36.7%)
	No	17 (38.6%)	7 (23.3%)
	Still waiting to know	0 (0.0%)	3 (10.0%)
	Don't know/Not sure	0 (0.0%)	2 (6.7%)
What is/are the reason(s) that you did not complete the treatment?	Treatment was not effective	0 (0.0%)	2 (100.0%)
	Other	1 (100.0%)	0 (0.0%)
What are the reason(s) that you have not had treatment for diabetic eye disease?	My doctor did not recommend any treatment	11 (68.8%)	1 (25.0%)
	Treatment would not be effective	2 (12.5%)	1 (25.0%)
	Treatment is not accessible	0 (0.0%)	1 (25.0%)
	Still waiting for treatment	2 (12.5%)	1 (25.0%)
	Too expensive	1 (6.3%)	0 (0.0%)
	I'm fearful of treatment	1 (6.3%)	0 (0.0%)
	Other	2 (12.5%)	0 (0.0%)

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

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

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

### Impact of Diabetic Eye Disease and Diabetic Macular Edema

Eighty-two percent of those diagnosed with DED or DME reported that their vision was affected (46% significantly, 36% slightly) (see Appendix Table 3.6).

Eighty-five percent of these respondents reported vision issues impacted their daily lives. Ways in which their lives were affected included: driving a vehicle (51%), leisure activities or exercise (50%), travelling (46%), household responsibilities such as cooking or cleaning (41%), working or keeping a job (36%), managing their underlying diabetes (28%) and social interactions with family or friends (19%) (see Table 7).

Table 7: Activities affected through vision impairment and loss

	All Respondents (n=78)
Driving (a car/vehicle)	40 (51.3%)
Leisure activities/exercise	39 (50.0%)
Travelling	36 (46.2%)
Household responsibilities, such as cooking or cleaning	32 (41.0%)
Work or keeping a job	28 (35.9%)
Managing my diabetes	22 (28.2%)
Social interactions with family/friends	15 (19.2%)
Other	8 (10.3%)
None	12 (15.4%)

Thirty-two percent of respondents with DED and 30% with DME were in paid employment compared with 55% of those without DED in paid employment (see Table 8 and Appendix EXP 5.1). One in three (36%) of those with vision complications, due to DED or DME, reported difficulties with working or keeping a job and of those diagnosed with DED 12% (n=7) were not working at all.

Eighty-six percent of those surveyed did not receive assistance from the government (see Appendix Table 4.5). While small in numbers, respondents who had received such assistance increased in those with DME (25%) and DED (17%) compared to those without DED (10%).

Ninety-four percent of respondents said they had no trouble paying for food at any time during the past year (see Appendix Table 4.6). The majority of respondents (80%) stated that they didn't feel their access to healthcare was affected by any factors, yet one in ten felt it was affected by their income (12%) (see Appendix Table 4.7).

Health (57%), family (11%), and money (11%) were the top three 'worries' on the mind 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=148)	With DED (n=60)	With DME (n=40)
Are you currently working?	Working for pay	81 (54.7%)	19 (31.7%)	12 (30.0%)
	Working without pay at home (e.g. housework, farming)	4 (2.7%)	0 (0.0%)	1 (2.5%)
	Volunteering	2 (1.4%)	5 (8.3%)	0 (0.0%)
	Retired	40 (27.0%)	29 (48.3%)	26 (65.0%)
	Student	10 (6.8%)	0 (0.0%)	0 (0.0%)
	Not working	11 (7.4%)	7 (11.7%)	1 (2.5%)
Question	Response	Without DED (n=140)	With DED (n=58)	With DME (n=36)
Do you receive assistance from the government?	Income assistance	4 (2.9%)	6 (10.3%)	2 (5.6%)
	Medical assistance	3 (2.1%)	0 (0.0%)	3 (8.3%)
	Food assistance	2 (1.4%)	0 (0.0%)	0 (0.0%)
	Housing assistance	3 (2.1%)	4 (6.9%)	0 (0.0%)
	Pension assistance	4 (2.9%)	3 (5.2%)	4 (11.1%)
	None of the above	126 (90.0%)	48 (82.8%)	27 (75.0%)
Question	Response	Without DED (n=149)	With DED (n=58)	With DME (n=39)
Did you have trouble paying for food at any time during the past year?	Yes	13 (8.7%)	2 (3.4%)	1 (2.6%)
-	No	136 (91.3%)	56 (96.6%)	38 (97.4%)

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

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

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

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

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

The CDC HRQOL-4 Core Modules of the "Healthy Days Measure" was used to capture information on self-reported quality of life, based on the number of unhealthy days within the last 30 days from when the survey was taken.

The reported health status varied depending on whether respondents had been diagnosed with DED or DME (see Table 9).

There was an association between DED and DME and increased likelihood of self-rated poor health and physical and mental unhealthy days.

Sixty-one percent of those with DED and DME reported their overall health as poor compared with 40% of people without DED. Three in four people with DED and DME experienced an impact on their physical health and 55% of those with DED and 60% of those with DME experienced a series of mentally unhealthy days compared with 45% of those without DED.

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

Health Status	Without DED	With DED	With DME
Self-rated health: Good	86 (59.7%)	23 (39.0%)	15 (39.5%)
Self-rated health: Poor	58 (40.3%)	36 (61.0%)	23 (60.5%)
Physically unhealthy days	69 (57.5%)	37 (74.0%)	25 (73.5%)
Mentally unhealthy days	58 (45.3%)	27 (55.1%)	21 (60.0%)
Unhealthy days	84 (67.7%)	41 (78.8%)	26 (76.5%)
Activity limitation days	48 (50.5%)	22 (55.0%)	14 (48.3%)

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

Compared with 44% of those without DED, 78% of people with DME and 72% of people with DED experienced limitations of their daily activities as a result of poor health. Where health or an associated condition impacted daily activities, the primary limitations were vision problems and back or neck problems. People living with DED and DME were more likely to have certain impairments beyond vision loss, and in particular, there was a marked increase in hypertension and heart problems (see Appendix Table EXP 2).

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

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

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



## Germany DR Barometer Findings:

#### Health Care Professionals

#### **Key Demographic Characteristics**

There were 75 health care professionals who answered at least one of the survey questions in Germany. Of these, seven were primary care providers (9.3%), 39 were diabetes specialist providers (52%) and ten were ophthalmologists (13%). The remainder 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 19.8 years, with the ophthalmologist group practicing for an average of 15.6 years (see Appendix PT 1.5).

All were well educated (71% with graduate or advanced degree), 42% were female and 58% male, and varied in age with 46% between 50 – 59 years (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 Provider	Ophthalmologist
All respondents		75 (100.0%)	7 (9.3%)	39 (52.0%)	10 (13.3%)
Age group	18 - 29 yrs.	3 (6.3%)	0 (0.0%)	0 (0.0%)	1 (14.3%)
	30 - 39 yrs.	5 (10.4%)	0 (0.0%)	3 (11.5%)	1 (14.3%)
	40 - 49 yrs.	10 (20.8%)	0 (0.0%)	5 (19.2%)	2 (28.6%)
	50 - 59 yrs.	22 (45.8%)	4 (100.0%)	12 (46.2%)	3 (42.9%)
	60 - 69 yrs.	8 (16.7%)	0 (0.0%)	6 (23.1%)	0 (0.0%)
Gender	Female	20 (41.7%)	1 (25.0%)	12 (46.2%)	0 (0.0%)
	Male	28 (58.3%)	3 (75.0%)	14 (53.8%)	7 (100.0%)
Education	Secondary School	5 (10.4%)	0 (0.0%)	1 (3.8%)	0 (0.0%)
	College/ University	9 (18.8%)	0 (0.0%)	5 (19.2%)	1 (14.3%)
	Graduate or advanced degree (e.g. PhD, MD, etc.)	34 (70.8%)	4 (100.0%)	20 (76.9%)	6 (85.7%)

#### Clinical Practice Characteristics

Thirty-seven percent of all health care professional have their main practice setting at a hospital and for ophthalmologists alone, it was an eye clinic (56%) or a hospital (33%). Seventy-seven percent of health care professionals work in an urban setting (see Appendix PT 2.1 and 2.2).

Most health care professionals worked in the private sector (40%). In contrast, fortyfour percent of ophthalmologists worked in the government (44%), private (22%), and combined or mixed (22%) sector (see Appendix PT 2.3).

The health care professionals reported that 68% of patients pay through insurance for services, 7.1% out-of-pocket (full fees), and 23% of patients don't pay for services. The situation was similar for ophthalmologists: 50% of patients pay through insurance for services, 13% out-of-pocket (full fees), and 25% of patients don't pay for services (see Appendix PT 2.7).

Health care professionals reported, on average, of seeing 152 patients per week, of which an estimated 52% of these patients had diabetes. Ophthalmologists saw an average of 169 patients per week and 16% of their patient population had diabetes (see Appendix PT 2.6).

For all health care professionals, the average wait time for an appointment was either more than one week but less than one month (33%) or less than one week (30%).

The average wait time for an appointment with an ophthalmologist was more than one week but less than one month in one-third of practices. In a further 22% of practices, the average wait time was between one and two months (see Table 11 and Appendix PT 2.5).

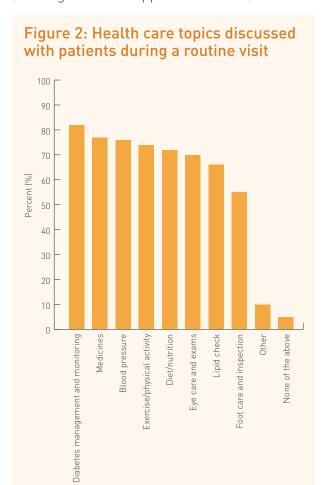
Table 11: Average wait times to schedule an appointment

Wait Time Intervals	All Respondents (n=34)	Ophthalmologist (n=9)
Less than 1 week	17 (29.8%)	0 (0.0%)
More than 1 week but less than 1 month	19 (33.3%)	3 (33.3%)
More than 1 month but less than 2 months	5 (8.8%)	2 (22.2%)
More than 2 months but less than 3 months	3 (5.3%)	0 (0.0%)
More than 3 months but less than 6 months	4 (7.0%)	1 (11.1%)
Do not take appointments	2 (3.5%)	0 (0.0%)
Other	4 (7.0%)	0 (0.0%)
Don't know/Not sure	3 (5.3%)	3 (33.3%)



#### **Patient Education Information**

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



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

Only forty-seven percent of providers reported that they had sufficient information about eye complications, 29% had information on diabetes, but that which was on eye complications was insufficient, and 12% reported that specific information on eye complications was not included in the available information. Just over 8% of providers did not have written information about diabetes and potential eye complications available for their patients.

Most ophthalmologists (88%) had written information about diabetes and potential eye complications, while 13% had information on diabetes but that which is on eye complications was insufficient. There were no ophthalmologists that reported not having written information available for their patients (see Table 12 and Appendix Table PT 2.11).

#### **Guidelines and Protocols**

Eighty-four percent of all providers, including 63% of ophthalmologists, had written protocols for the management of diabetes available, which were used by staff. However, 12% of all providers had no such protocols (see Appendix PT 2.12).

One third of providers (34%) did not have written protocols for the management of diabetes-related vision issues. Fifty-four percent of health care professionals had written protocols available that were used by staff and 6% had protocols available but not used by staff.

For ophthalmologists, 75% had written protocols available that were used by staff. Similar to all providers, 25% of ophthalmologists did not have access to protocols on diabetes-related vision issues (see Table 12 and Appendix PT 2.13).

Table 12: Availability and use of information and protocols

Question	Response	All Respondents (n=49)	Ophthalmologist (n=8)
Is there written information about diabetes available for patients in your main practice?	Yes, and information on eye complications is sufficient	23 [46.9%]	7 (87.5%)
	Yes, but information on eye complications is not sufficient	14 (28.6%)	1 (12.5%)
	Yes, but no information on eye complications is included	6 (12.2%)	0 (0.0%)
	No written information is available for patients	4 (8.2%)	0 (0.0%)
	Don't know/Not sure	2 (4.1%)	0 (0.0%)
Question	Response	All Respondents (n=50)	Ophthalmologist (n=8)
Do you have written protocols/guidelines for detection and management of diabetes-related vision issues available in your main practice?	Yes, available and used by staff	27 (54.0%)	6 (75.0%)
	Yes, available but not used by staff	3 (6.0%)	0 (0.0%)
	Not available	17 (34.0%)	2 (25.0%)
·	Don't know/Not sure	3 (6.0%)	0 (0.0%)



### Screening Protocols and Barriers in the Care Pathway

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

Most providers, for patients with type 1 (60%) or type 2 (78%) diabetes, reported that the initial eye exam should occur at the time of the diagnosis of diabetes (see Appendix PT 2.14).

Overall, 84% of health care professionals, including 63% of ophthalmologists, reported that follow-up eye examinations should be conducted every year. Seventy-five percent of ophthalmologists, and 24% of all health care professionals, screen patients for DR (see Appendix PT 2.15 and 2.16).

For all health care professionals, 47% reported to send appointment reminders and 49% do not. Eight-six percent of the providers, including all of the ophthalmologists, shared information to optimise patient care management (see Appendix PT 2.19 and 2.20).

The most common patient characteristics influencing the referral process for eye complications were: diabetes duration (54%), the presence of comorbidities such as hypertension (38%), high glucose levels (38%), a patient's age (35%), and a patient's gender (4.2%).

The findings were similar for ophthalmologists: diabetes duration (100%), a patient's age (71%), the presence of comorbidities such as hypertension (71%), high glucose levels (71%), and a patient's gender (14%) (see Appendix PT 2.17).

As reported by all health care professionals, the major barriers to optimizing eye health faced by patients with diabetes were: long wait times for an appointment (48%), the limited access to eye specialists (30%), and patient feels that eye exams are not important (30%).

Other common barriers were: a general lack of knowledge or awareness (21%), patient feels that eye complications are unlikely (21%), patients have competing responsibilities and priorities (16%), the cost of care (14%), long wait times on the day of the visit (14%), the proximity to care (11%), the referral process (11%), clinics are too small or lack necessary equipment or staff (11%).

Similarly, ophthalmologists reported: the cost of care and a general lack of knowledge or awareness (50%), the proximity to care (33%), the long wait times on the day of the visit (33%), patient feels that eye complications are unlikely (33%), and patient feels that eye exams are not important (33%) (see Table 13 and Appendix PT 2.18).

Table 13: Major barriers to optimising eye health

Response	All Respondents (n=44)	Ophthalmologists (n=6)
Long wait time for appointment	21 (47.7%)	1 (16.7%)
Limited access to eye specialists	13 (29.5%)	1 (16.7%)
Patients feel eye exams are not important	13 (29.5%)	2 (33.3%)
Lack of knowledge and/or awareness	9 (20.5%)	3 (50.0%)
Patients feel eye complications are unlikely	9 (20.5%)	2 (33.3%)
Patients have competing responsibilities and priorities	7 (15.9%)	1 (16.7%)
Cost of care	6 (13.6%)	3 (50.0%)
Long wait time on the day of visit	6 (13.6%)	2 (33.3%)
Proximity to care	5 (11.4%)	2 (33.3%)
Referral process	5 (11.4%)	0 (0.0%)
Clinic too small or lack necessary equipment/staff	5 (11.4%)	1 (16.7%)
Recommended treatments are not available	4 (9.1%)	0 (0.0%)
Patients fear of treatment/results	4 (9.1%)	1 (16.7%)
Limited access to diabetes specialists	3 (6.8%)	1 (16.7%)
Patients feel they are a burden on family/friends	1 (2.3%)	1 (16.7%)
Other	4 (9.1%)	0 (0.0%)



## Germany DR Barometer Findings:

#### **Ophthalmologists**

#### Screening

There were six ophthalmologists who answered at least one of the supplementary questions (see Appendix PT 4.1 to PT 4.14).

The ophthalmologists reported that an average of 15% of their patients had DR and 11% had DME (see Appendix PT 4.1 and PT 4.2).

The most common wait time for a screening appointment for DED was more than one week but less than one month (57%) while 29% stated between one and two months. Seventy-one percent of ophthalmologists reported that there was no wait from the time of screening to diagnosis, 14% (n=1) reported a wait time of less than one week. (See Appendix PT 4.3 and PT 4.4)

#### **Treatment and Challenges**

Eighty-six percent of ophthalmologists personally administer treatment for diabetic retinopathy. The most common factors influencing how they treat patients with DR or DME are: the presence of comorbidities such as hypertension, (60%), diabetes duration (40%), a patient's age (40%), high glucose levels (40%), and a patient's ability to adhere to recommendations (40%) (see Appendix PT 4.6 and 4.7).

The most common outreach venues for screening for DED were reported to be at vision centres (50%), health fairs for all (17%), and health fairs for people with diabetes (see Appendix PT 4.13).

All ophthalmologists reported that they screen patients for DR based on fundoscopy through dilated pupils. Additionally, 83% use optical coherence tomography and 50% use fluorescein angiography. Eighty-three percent of ophthalmologists reported that they treat DR and DME based on both visual and anatomical outcomes (see Appendix PT 4.8 and PT 4.9).

Eighty-three percent of ophthalmologists reported that the majority of their patients present when visual problems have already occurred, while 17% (n=1) reported that patients present in time for the screening (see Appendix PT 4.10).

Sixty-seven percent of the ophthalmologists had received specific training in the treatment and diagnosis of DR and or DME, of which 75% had received training within the past year and 25% more than one year ago but less than five years. Fifty percent would be interested in online education and certification on DME, angiogenesis and anti-VEGF therapies (see Appendix PT 4.11 and PT 4.12).

Ophthalmologists reported that the greatest challenges for improving patient outcomes in DED were late diagnosis (83%, n=5), and no universal guidelines on referral/screening (50%, n=3) (see Table 14 and Appendix PT 4.14).

Table 14: Challenges for improving outcomes in DED

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



## Germany DR Barometer Summary

In Germany, 290 adults with diabetes and 75 health care professionals provided insight into the experiences of living with, managing and treating diabetes, DR and DME.

The results help to understand the level of awareness, and access and barriers to diabetes management, including screening for DR and DME and timely treatment.

In the coming decades, Germany will experience a rapid increase in their ageing population. By 2050, there will be ~40 million people aged 60 years and older making up ~54% of Germany's population while people aged 14 to 59 years expected to decrease by over ten percent.

In 2015, Germany also had the fourth-highest number of people with diabetes in the European region with over 6.5 million cases of diabetes in Germany and an estimated number of undiagnosed cases of around 2.5 million. Germany's high number of people with diabetes is exemplified by the estimated 35 billion USD spent on diabetes related health expenditures which is predicted to increase to 36 billion USD by 2040.

The DR Barometer findings indicate that overall a younger population was more likely to be associated with type 1 diabetes, which was the opposite of those with type 2 diabetes, which tended to be an older population. The study also showed that the longer the time since diabetes was diagnosed, the greater the likelihood for DED and DME to be detected. This is an important, and well-known, finding in the context of Germany's rapidly ageing population.

People were most often informed about their diabetes condition by a doctor or nurse, but it is important to note that respondents valued their health educator as a valuable source of information. A trend globally, which was reflected in the German study, was the increasing use of the internet by almost half (47%) of the respondents.

Sixty-four percent of respondents were currently enrolled in diabetes management programmes and most (84%) noted there was education on the importance of screening for diabetic eye complications.

Many of those surveyed struggled with the management of their diabetic condition with some issues that were within their personal control such as difficulty in eating the right foods and balancing other priorities, such as work and family, without compromising their health. In addition, the nature of the healthcare system, including the high cost of care and the long wait times for an appointment, were challenges.

There was not only a relatively high awareness of the complications associated with diabetes but vision loss specifically was feared two times more than cardiovascular disease or stroke and three times more than kidney disease.

There was also a considerable increase in the frequency of people with DED and DME experiencing serious and life changing complications compared to people without DED. The frequency of neuropathy increased from 10% in those without DED to 38% in DED and 48% in DME. Likewise, the frequency of cardiovascular disease increased from 10% in people without DED to 27% in those with DED and to 18% with DME.

Knowing that diabetes-related vision loss is preventable addressing barriers to eye screening is an important policy issue. While most respondents had received an eye exam, which is understandable considering the purposeful sample, there still remained many barriers including long wait times, either to schedule an appointment or on the day of the visit, and a general fear of treatment or the results. Given that 84% of all providers recommend annual screenings, it was a surprise finding that less than half-sent reminders to their patients to schedule an appointment.

The relationship between the patient and the health care professional is critical to realistic and optimal patient outcomes. It was therefore surprising that more than a quarter of patients surveyed had either never had a conversation about eye complications with their health care professional or only did so after symptoms arose.

Furthermore, health education and information were reported by patients as the most important tool to improve the management of one's diabetes yet one in five respondents did not receive any information on eye complications from traditional sources, such as their doctor or nurse. Likewise, half of the ophthalmologists reported one of the major barriers to optimising eye health was a lack of knowledge or awareness and yet less than half of all providers had sufficient information on diabetes-related eye health available for their patients.

Knowledge and guidance was not only an issue for patient as one in three providers said they did not have any written protocols or guidelines in the management of diabetes-related vision issues.

Twenty-one percent of respondents reported to have been diagnosed with DED and a further 14% with DME. Eighty-five percent of these respondents reported vision issues which impacted their daily lives, such as: driving a vehicle, leisure activities, and travelling, household responsibilities, working or keeping a job, and managing their underlying diabetes, including the ability to exercise. Almost two-thirds of those with DED and DME reported their overall health as poor compared with 40% of people without DED.

Health, family, and money were the top three 'worries' on the mind of the respondents surveyed.

Eighty-three percent of ophthalmologists stated the majority of their patients present for screening when visual problems have already occurred rather than in time for the screening and four in five cited late diagnoses as one of the greatest challenges for improving outcomes in DED, followed by a lack of universal guidelines.

The majority of those with DME would prefer proactive treatment to prevent further vision loss rather than reactive treatment once further vision loss occurred.

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.



## References and Acknowledgement

- <sup>1</sup> Statistisches Bundesamt. (2016). *Current Population*. Retrieved from: https://www.destatis.de/EN/FactsFigures/SocietyState/Population/CurrentPopulation/CurrentPopulation.html
- <sup>2</sup> United Nations. (2015). World Population Prospects, Key Findings and Advanced Tables. Retrieved from: https://esa.un.org/ unpd/wpp/publications/files/key\_findings\_ wpp\_2015.pdf
- <sup>3</sup> International Diabetes Federation. (2015). *IDF Diabetes Atlas*. Retrieved from: http://www.diabetesatlas.org/

The IFA, IDF and IAPB would like to acknowledge and thank the many organisations and health care professionals from Germany that assisted in the dissemination of patient and provider surveys.

In addition we especially recognise the Deutscher Blinden- und Sehbehindertenverband e.V. (DBSV), Deutshce Diabetes Hilfe, Professor Focke Ziemssen and Professor Hans-Peter Hammes for their specific collaboration. All of these contributions and support were pivotal to the success of the DR Barometer Study.

## Appendices



# The Diabetic Retinopathy Barometer Survey: Appendices for Germany

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

#### **Table 1.1**

Survey Information	Number of Respondents (%)
All valid respondents [1]	313 (100.0%)
Respondents aged 18 or over	310 (99.0%)
Respondents with diabetes	291 (93.0%)

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

Table 1.2

Survey Information	Number of Respondents (%)
All valid respondents	313 (100.0%)
Included in Diabetic Analysis Set	290 (92.7%)
Excluded from Diabetic Analysis Set	23 (7.3%)
Reasons for exclusion from diabetic analysis set	•
Under 18 years of age	3
Not diagnosed with diabetes	11
Missing information on diabetes diagnosis	8
Gestational diabetes only	1

#### Table 1.3

Survey Information	Number of Respondents (%)
Diabetic Analysis Set	290 (100.0%)
World Bank Income Group: High Income	290 (100.0%)
Persons with diabetic eye disease (DED)	62 (21.4%)
Persons with diabetic macular edema (DME)	40 (13.8%)
Persons with Type I diabetes	172 (59.3%)
Persons with Type II diabetes	113 (39.0%)
Persons not seeing health care professional for diabetes	7 (2.4%)
Persons seeing health care professional for diabetes	279 (96.2%)
Persons with eye disease & not received treatment	20 (6.9%)

Survey Information	Number of Respondents (%)
Persons with eye disease & received treatment	77 (26.6%)

#### Table 2.1

Question	Response	Number of Respondents (%)
With which type of diabetes have you been diagnosed?	Type I	172 (59.3)
	Type II	113 (39.0)
	Don't know/Not sure	5 (1.7)
	Total Valid Response	290 (100.0)

#### Table 2.2

Question	Response	Number of Respondents (%)
When was your diabetes diagnosed?	Within the last year	13 (4.6)
	1 - 5 years ago	44 (15.4)
	6 - 10 years ago	32 (11.2)
	11 - 15 years ago	37 (13.0)
	16 - 20 years ago	23 (8.1)
	21 years ago or longer	132 (46.3)
	Don't know/Not sure	4 (1.4)
	Total Valid Response	285 (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	279 (97.6)
	No	7 (2.4)
	Total Valid Response	286 (100.0)
	Total missing	4
What kind of health care professional?	General/Family Doctor	78 (28.2)
	Diabetes Specialist	195 (70.4)



Question	Response	Number of Respondents (%)
	Other	2 (0.7)
	Don't know/Not sure of kind	2 (0.7)
	Total Valid Response	277 (100.0)
	Total missing	13

**Table 2.3.2** 

Type of health care professional	Times per year seen for diabetes	Value
General/Family Doctor	Total valid numeric response (n)	66
	Mean	4.7
	SD	3.4
	Median	4.0
	Min	1
	Max	24
	Don't know/Not sure	5
	Total missing	7
Diabetes Specialist	Total valid numeric response (n)	165
	Mean	4.7
	SD	2.3
	Median	4.0
	Min	1
	Max	15
	Don't know/Not sure	5
	Total missing	25
Other	Total valid numeric response (n)	2
	Mean	12.0
	SD	11.3
	Median	12.0
	Min	4
	Max	20
Don't know/Not sure of kind	Total valid numeric response (n)	0
	Mean	
	SD	

Type of health care professional	Times per year seen for diabetes	Value
	Median	
	Min	
	Max	
	Total missing	2

Table 2.4

Question	Response	Number of Respondents (%)
How have you received information about diabetes?	Doctor or nurse	212 (76.3%)
	Health educator	164 (59.0%)
	Nutritionist or dietitian	59 (21.2%)
	Diabetes organization or other health organization	89 (32.0%)
	Family/Friends/Neighbors	42 (15.1%)
	TV/Radio/Newspaper/Magazines	64 (23.0%)
	Internet	130 (46.8%)
Social media (e.g. Facebook, Twit blogs)  Other  Pharmacist	Social media (e.g. Facebook, Twitter, blogs)	33 (11.9%)
	Other	20 (7.2%)
	Pharmacist	19 (6.8%)
	None of the above	5 (1.8%)
	Total Valid Response	278 (100.0%)
	Total missing	12

Table 2.5

Question	Response	Number of Respondents (%)
How do you manage your diabetes?	Diet	136 (48.7%)
	Oral medicine	83 (29.7%)
	Exercise	98 (35.1%)
	Insulin	217 (77.8%)
	Natural/Herbal medicine	4 (1.4%)
	Other	1 (0.4%)
	None of the above	2 (0.7%)



Question	Response	Number of Respondents (%)
	Total Valid Response	279 (100.0%)
	Total missing	11

#### Table 2.6

Question	Response	Number of Respondents (%)
Are you currently enrolled in a diabetes patient management support programme?	Yes	178 (63.8)
	No	101 (36.2)
	Total Valid Response	279 (100.0)
	Total missing	11
Who sponsors the programme?	Hospital support program	5 (3.0)
	Clinic support program	7 (4.2)
	Pharmaceutical support program	1 (0.6)
	Patient organization support program	15 (9.1)
	Don't know/Not sure	137 (83.0)
	Total Valid Response	165 (100.0)
	Total missing	125
Does the programme include education on the importance of screening for diabetic eye complications?	Yes	146 (83.9)
	No	28 (16.1)
	Total Valid Response	174 (100.0)
	Total missing	116

#### 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	272 (99.6%)
	Less than 6 months	248 (90.8%)
	6 - 12 months	6 (2.2%)

Test	Response	Number of Respondents (%)
	Greater than 12 months	13 (4.8%)
	Total valid response	267 (97.8%)
	Total missing	23
	No	1 (0.4%)
	Total valid response	273 (100.0%)
	Total missing	17
Urine check	Yes	254 (95.1%)
	Less than 6 months	175 (65.5%)
	6 - 12 months	54 (20.2%)
	Greater than 12 months	19 (7.1%)
	Total valid response	248 (92.9%)
	Total missing	42
	No	11 (4.1%)
	Don't know/Not sure	2 (0.7%)
	Total valid response	267 (100.0%)
	Total missing	23
Weight check	Yes	256 (95.5%)
	Less than 6 months	212 (79.1%)
	6 - 12 months	19 (7.1%)
	Greater than 12 months	19 (7.1%)
	Total valid response	250 (93.3%)
	Total missing	40
	No	11 (4.1%)
	Don't know/Not sure	1 (0.4%)
	Total valid	268 (100.0%)



Test	Response	Number of Respondents (%)
	response	
	Total missing	22
Blood pressure check	Yes	267 (98.2%)
	Less than 6 months	237 (87.1%)
	6 - 12 months	19 (7.0%)
	Greater than 12 months	3 (1.1%)
	Total valid response	259 (95.2%)
	Total missing	31
	No	4 (1.5%)
	Don't know/Not sure	1 (0.4%)
	Total valid response	272 (100.0%)
	Total missing	18
Foot check	Yes	245 (90.7%)
	Less than 6 months	152 (56.3%)
	6 - 12 months	65 (24.1%)
	Greater than 12 months	22 (8.1%)
	Total valid response	239 (88.5%)
	Total missing	51
	No	24 (8.9%)
	Don't know/Not sure	1 (0.4%)
	Total valid response	270 (100.0%)
	Total missing	20
Eye check	Yes	256 (95.5%)
	Less than 6 months	164 (61.2%)
	6 - 12 months	68 (25.4%)

Test	Response	Number of Respondents (%)
	Greater than 12 months	19 (7.1%)
	Total valid response	251 (93.7%)
	Total missing	39
	No	10 (3.7%)
	Don't know/Not sure	2 (0.7%)
	Total valid response	268 (100.0%)
	Total missing	22

# Table 2.8

Question	Response	Number of Respondents (%)
How well do you think your diabetes is controlled?	Very well	84 (31.7%)
	Well	136 (51.3%)
	Not very well	33 (12.5%)
	Not well at all	5 (1.9%)
	Don't know/Not sure	7 (2.6%)
	Total Valid Response	265 (100.0%)
	Total missing	25

# Table 2.9

Question	Response	Number of Respondents (%)
What are the main challenges you face in controlling your diabetes?	High cost of care	70 (26.4%)
	No insurance	6 (2.3%)
	Travel to my regular doctor or specialist is difficult	39 (14.7%)
	Long wait time for an appointment to see my doctor or specialist	54 (20.4%)
	Health services needed are not	6 (2.3%)



Question	Response	Number of Respondents (%)
	available	
	Don't know enough about diabetes	8 (3.0%)
	Too hard to eat the right things	80 (30.2%)
	Too many other things to do	50 (18.9%)
	Stigma or discrimination because of diabetes	17 (6.4%)
	Don't want to think about having diabetes	31 (11.7%)
	Other	48 (18.1%)
	Total Valid Response	265 (100.0%)
	Total missing	25

### **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	115 (43.9%)
	Support groups	50 (19.1%)
	Support from family or friends	112 (42.7%)
	Health education and information	93 (35.5%)
	Mobile services (services that travel to or near your home)	3 (1.1%)
	Coordination of healthcare and services by a professional	32 (12.2%)
	Emergency helpline	4 (1.5%)
	Other	31 (11.8%)
	None	42 (16.0%)
	Total Valid Response	262 (100.0%)
	Total missing	28

# **Table 2.11**

Question	Response	Number of Respondents (%)
What complications (or problems), to your knowledge, arise from diabetes?	Amputation	226 (85.6%)

Question	Response	Number of Respondents (%)
	Foot ulcers	163 (61.7%)
	Increased risk of broken bones or fractures	32 (12.1%)
	Loss of feeling in hands or toes (neuropathy)	233 (88.3%)
	Vision loss	248 (93.9%)
	Irritable bowel disease	97 (36.7%)
	Kidney disease	226 (85.6%)
	Cardiovascular disease/Stroke	206 (78.0%)
	Other	25 (9.5%)
	Don't know/Not sure	1 (0.4%)
	None	5 (1.9%)
	Total Valid Response	264 (100.0%)
	Total missing	26

**Table 2.12** 

Question	Response	Number of Respondents (%)
Which complication of diabetes are you most concerned about?	Amputation	15 (5.7)
	Increased risk of broken bones or fractures	1 (0.4)
	Loss of feeling in hands or toes (neuropathy)	6 (2.3)
	Vision loss	135 (51.3)
	Irritable bowel disease	3 (1.1)
	Kidney disease	37 (14.1)
	Cardiovascular disease/Stroke	50 (19.0)
	Other	1 (0.4)
	Don't know/Not sure	3 (1.1)
	None	12 (4.6)
	Total Valid Response	263 (100.0)
	Total missing	27



**Table 2.13** 

Question	Response	Number of Respondents (%)
Which of the following complications of diabetes do you have?	Amputation	3 (1.2%)
	Foot ulcers	4 (1.5%)
	Broken bones or fractures	3 (1.2%)
	Loss of feeling in hands or toes (neuropathy)	58 (22.4%)
	Vision loss	68 (26.3%)
	Irritable bowel disease	35 (13.5%)
	Kidney disease	17 (6.6%)
	Cardiovascular disease/Stroke	39 (15.1%)
	Other	16 (6.2%)
	Don't know/Not sure	5 (1.9%)
	None	118 (45.6%)
	Total Valid Response	259 (100.0%)
	Total missing	31

**Table 2.14** 

Question	Response	Number of Respondents (%)
How often do you discuss the possibility of eye complications with your health care professional?	Every visit	52 (20.1%)
	Multiple times per year	63 (24.3%)
	Once per year	65 (25.1%)
	Only when symptoms arise	42 (16.2%)
	Never	33 (12.7%)
	Don't know/Not sure	4 (1.5%)
	Total Valid Response	259 (100.0%)
	Total missing	31

**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 (5.3%)
	I do what I can to prevent vision problems (e.g. get routine screenings, visit specialists)	227 (93.4%)
	I do not make any special effort to prevent vision problems	14 (5.8%)
	Total Valid Response	243 (100.0%)
	Total missing	47

### **Table 2.16**

Question	Response	Number of Respondents (%)
What type of health insurance do you have?	Public	223 (86.1)
	Public - Private	9 (3.5)
	Private	25 (9.7)
	None	2 (0.8)
	Total Valid Response	259 (100.0)
	Total missing	31

### **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	71 (28.3)
	Insurance pays total cost	142 (56.6)
	Insurance and out-of- pocket/cash (e.g. co-pays)	35 (13.9)
	Out-of-pocket only (pay cash for all care)	2 (0.8)
	Don't know/Not Sure	1 (0.4)
	Total Valid Response	251 (100.0)
	Total missing	39
Specialist medical visits (e.g. eye doctor, gynecologist, urologist)	Care is free	59 (23.7)



Question	Response	Number of Respondents (%)
	Insurance pays total cost	124 (49.8)
	Insurance and out-of- pocket/cash (e.g. co-pays)	62 (24.9)
	Out-of-pocket only (pay cash for all care)	3 (1.2)
	Don't know/Not Sure	1 (0.4)
	Total Valid Response	249 (100.0)
	Total missing	41
Medicines	Care is free	16 (6.4)
	Insurance pays total cost	46 (18.4)
	Insurance and out-of- pocket/cash (e.g. co-pays)	178 (71.2)
	Out-of-pocket only (pay cash for all care)	8 (3.2)
	Do not use service	2 (0.8)
	Total Valid Response	250 (100.0)
	Total missing	40
Medical supplies (e.g. blood glucose meter/strips)	Care is free	39 (16.0)
	Insurance pays total cost	75 (30.7)
	Insurance and out-of- pocket/cash (e.g. co-pays)	93 (38.1)
	Out-of-pocket only (pay cash for all care)	21 (8.6)
	Do not use service	13 (5.3)
	Don't know/Not Sure	3 (1.2)
	Total Valid Response	244 (100.0)
	Total missing	46
Procedures	Care is free	26 (11.3)
	Insurance pays total cost	64 (27.7)
	Insurance and out-of- pocket/cash (e.g. co-pays)	31 (13.4)
	Out-of-pocket only (pay cash for all care)	2 (0.9)
	Do not use service	88 (38.1)
	Don't know/Not Sure	20 (8.7)

100.0) 5.2) 46.2) 0.2)
46.2) 0.2)
46.2) 0.2)
0.2)
3)
.2)
))
100.0)
4.4)
42.1)
.5)
')
9.4)
))
100.0)
.0)
6.3)
.7)
57.5)
.4)
100.0)

Table 3.1

Question	Response	Number of Respondents (%)
Are you aware of any government sponsored screening	Yes	185 (72.8%)



Question	Response	Number of Respondents (%)
programs for diabetic eye disease (diabetic retinopathy)?		
	No	69 (27.2%)
	Total valid response	254 (100.0%)
	Total missing	36

Question	Response	Number of Respondents (%)
Have you ever had an eye exam for diabetic eye disease?	Yes	241 (93.8%)
	No	16 (6.2%)
	Total valid response	257 (100.0%)
	Total missing	33
How long ago was your last eye exam?	Within the last year	210 (88.2%)
	More than 1 year ago but less than 2 years	18 (7.6%)
	More than 2 years ago but less than 3 years	1 (0.4%)
	More than 3 years ago but less than 5 years	2 (0.8%)
	Five or more years ago	6 (2.5%)
	Don't know/Not sure	1 (0.4%)
	Total valid response	238 (100.0%)
	Total missing	52
Who did the last exam?	Eye doctor/Eye clinic	239 (99.6%)
	Other	1 (0.4%)
	Total valid response	240 (100.0%)
	Total missing	50

Question	Response	Number of Respondents (%)
Have you ever had a dilated eye exam, where your eyes are examined after eye drops?	Yes	243 (96.0%)

Question	Response	Number of Respondents (%)
	No	7 (2.8%)
	Don't know/Not sure	3 (1.2%)
	Total valid response	253 (100.0%)
	Total missing	37

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	245 (96.5%)
	Every two years	1 (0.4%)
	Only when symptoms occur	2 (0.8%)
	Never	2 (0.8%)
	Don't know/Not sure	4 (1.6%)
	Total valid response	254 (100.0%)
	Total missing	36

Question	Response	Number of Respondents (%)
For you, what are the biggest barriers to eye exams?	They are expensive	24 (11.7%)
	Eye exams are not available near my home	10 (4.9%)
	Long wait time for appointment	103 (50.2%)
	Long wait time on the day of the visit	89 (43.4%)
	Referral process is complicated or takes too long	6 (2.9%)
	Recommended treatments for eye problems are not available	11 (5.4%)
	Don't know much about my condition	13 (6.3%)
	Fear of treatment/results	45 (22.0%)



Question	Response	Number of Respondents (%)
	Burden on my family/friends	17 (8.3%)
	Limited access to diabetes specialists	12 (5.9%)
	I'm not likely to have eye complications	4 (2.0%)
	Eye exams are not important	4 (2.0%)
	Too many other things to do or worry about	16 (7.8%)
	Clinics are too small or lack necessary equipment/staff	4 (2.0%)
	Other	33 (16.1%)
	Total valid response	205 (100.0%)
	Total missing	85

Question	Response	Number of Respondents (%)
Have you been diagnosed with diabetic eye disease?	Yes	99 (38.8%)
	No	156 (61.2%)
	Total valid response	255 (100.0%)
	Total missing	35
Has your diabetic eye disease affected your vision?	Yes, slightly	36 (36.4%)
	Yes, significantly	45 (45.5%)
	No	18 (18.2%)
	Total valid response	99 (100.0%)
	Total missing	191
Have vision issues caused you to have difficulty with any of the following?	Traveling	36 (46.2%)
	Household responsibilities, such as cooking or cleaning	32 (41.0%)
	Social interactions with family/friends	15 (19.2%)
	Leisure activities/exercise	39 (50.0%)
	Work or keeping a job	28 (35.9%)
	Managing my diabetes	22 (28.2%)

Question	Response	Number of Respondents (%)
	Other	8 (10.3%)
	None	12 (15.4%)
	Driving (a car/vehicle)	40 (51.3%)
	Total valid response	78 (100.0%)
	Total missing	212

Question	Response	Number of Respondents (%)
Have you had any treatment for diabetic eye disease?	Yes	77 (77.8%)
	No	20 (20.2%)
	Don't know/Not sure	2 (2.0%)
	Total valid response	99 (100.0%)
	Total missing	191
What treatment did you receive?	Laser	67 (87.0%)
	Injection in the eye (Anti- VEGF)	24 (31.2%)
	Surgery	31 (40.3%)
	Other	10 (13.0%)
	Total valid response	77 (100.0%)
	Total missing	213
Did you complete the treatment?	Yes	48 (62.3%)
	No	3 (3.9%)
	Still receiving treatment	25 (32.5%)
	Don't know/Not sure	1 (1.3%)
	Total valid response	77 (100.0%)
	Total missing	213
Do you feel that the treatment worked?	Yes, and vision improved	13 (17.6%)
	Yes, but vision stayed the same	32 (43.2%)
	No	24 (32.4%)
	Still waiting to know	3 (4.1%)
	Don't know/Not sure	2 (2.7%)



Question	Response	Number of Respondents (%)
	Total valid response	74 (100.0%)
	Total missing	216
What is/are the reason(s) that you did not complete the treatment?	Treatment was not effective	2 (66.7%)
	Other	1 (33.3%)
	Total valid response	3 (100.0%)
	Total missing	287
What are the reason(s) that you have not had treatment for diabetic eye disease?	My doctor did not recommend any treatment	12 (60.0%)
	Treatment would not be effective	3 (15.0%)
	Treatment is not accessible	1 (5.0%)
	Still waiting for treatment	3 (15.0%)
	Too expensive	1 (5.0%)
	I'm fearful of treatment	1 (5.0%)
	Other	2 (10.0%)
	Total valid response	20 (100.0%)
	Total missing	270

Question	Response	Number of Respondents (%)
Have you been diagnosed with diabetic macular edema?	Yes	40 (15.9%)
	No	178 (70.6%)
	Don't know/Not sure	34 (13.5%)
	Total valid response	252 (100.0%)
	Total missing	38
If Yes, which of the following would you prefer	Treatment to prevent further vision loss	33 (84.6%)
	Only treatment when vision loss has occurred	3 (7.7%)
	Don't know/Not sure	3 (7.7%)
	Total valid response	39 (100.0%)
	Total missing	251

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	118 (50.4%)
	Health educator	16 (6.8%)
	Diabetes organization or other health organization	55 (23.5%)
	Family/Friends/Neighbors	6 (2.6%)
	TV/Radio/Newspaper/Magazines	39 (16.7%)
	Internet	84 (35.9%)
	Other	11 (4.7%)
	None of the above	50 (21.4%)
	Total valid response	234 (100.0%)
	Total missing	56

Table 4.1

Question	Response	Number of Respondents (%)
What is your gender?	Female	128 (51.4)
	Male	121 (48.6)
	Total Valid Response	249 (100.0)
	Total missing	41
Please indicate your age	18 - 29	31 (10.7)
	30 - 39	38 (13.1)
	40 - 49	49 (16.9)
	50 - 59	55 (19.0)
	60 - 69	80 (27.6)
	70 - 79	27 (9.3)
	80 - 89	10 (3.4)
	Total Valid Response	290 (100.0)

Table 4.2

Question	Response	Number of Respondents (%)
----------	----------	---------------------------



Question	Response	Number of Respondents (%)
Where do you live?	Urban setting	180 (72.0)
	Non-urban setting	70 (28.0)
	Total Valid Response	250 (100.0)
	Total missing	40

#### Table 4.3

Question	Response	Number of Respondents (%)
What is the highest level of education you completed?	Did not complete primary school	3 (1.2)
	Primary school	135 (54.4)
	Secondary school	27 (10.9)
	College/University	73 (29.4)
	Graduate or post-graduate	10 (4.0)
	Total valid response	248 (100.0)
	Total missing	42

#### Table 4.4

Question	Response	Number of Respondents (%)
Are you currently working?	Working for pay	112 (45.2)
	Working without pay at home (e.g. housework, farming)	5 (2.0)
	Volunteering	7 (2.8)
	Retired	95 (38.3)
	Student	10 (4.0)
	Not working	19 (7.7)
	Total Valid Response	248 (100.0)
	Total missing	42

### Table 4.5

Question	Response	Number of Respondents (%)
Do you receive assistance from the government?	Income assistance	12 (5.1%)

Question	Response	Number of Respondents (%)
	Medical assistance	6 (2.6%)
	Food assistance	2 (0.9%)
	Housing assistance	7 (3.0%)
	Pension assistance	11 (4.7%)
	None of the above	201 (85.9%)
	Total valid response	234 (100.0%)
	Total missing	56

# Table 4.6

Question	Response	Number of Respondents (%)
Did you have trouble paying for food at anytime during the past year?	Yes	16 (6.5)
	No	230 (93.5)
	Total Valid Response	246 (100.0)
	Total missing	44

### Table 4.7

Question	Response	Number of Respondents (%)
Do you feel that your access to health care is negatively affected by any of the following?	Age	8 (3.3)
	Education	1 (0.4)
	Ethnicity	1 (0.4)
	Gender	2 (0.8)
	Income	30 (12.4)
	Language you speak	2 (0.8)
	Place of birth	1 (0.4)
	Place where you live	20 (8.3)
	Race	2 (0.8)
	Religion	2 (0.8)



Question	Response	Number of Respondents (%)
	Sexual orientation	1 (0.4)
	Tribal affiliation	2 (0.8)
	None of the above	192 (79.7)
	Total valid response	241 (100.0)
	Total missing	49

#### Table 4.8

Question	Response	Number of Respondents (%)
Which of the following do you worry about most?	Food	4 (1.6)
	Housing	1 (0.4)
	Money	26 (10.5)
	Health	140 (56.7)
	Family	28 (11.3)
	Other	5 (2.0)
	None of the above	43 (17.4)
	Total Valid Response	247 (100.0)
	Total missing	43

### Table 5.1

Question	Response	Number of Respondents (%)
In general, would you say your health is:	Excellent	3 (1.2%)
	Very good	23 (9.5%)
	Good	98 (40.7%)
	Total good health	124 (51.5%)
	Fair	81 (33.6%)
	Poor	36 (14.9%)
	Fair or poor health	117 (48.5%)
	Total valid response	241 (100.0%)
	Total missing	49

Table 5.2

Question	Response	Number of Respondents (%)
How many days during last 30 days was your physical health not good	Any unhealthy days	131 (64.2%)
	1-5 unhealthy days	34 (16.7%)
	6-10 unhealthy days	22 (10.8%)
	11-20 unhealthy days	16 (7.8%)
	21-30 unhealthy days	59 (28.9%)
	No unhealthy days	73 (35.8%)
	Total valid response	204 (100.0%)
	Total missing	86

**Table 5.3.1** 

Question	Response	Number of Respondents (%)
How many days during last 30 days was your mental health not good	Any unhealthy days	106 (50.0%)
	1-5 unhealthy days	35 (16.5%)
	6-10 unhealthy days	12 (5.7%)
	11-20 unhealthy days	20 (9.4%)
	21-30 unhealthy days	39 (18.4%)
	No unhealthy days	106 (50.0%)
	Total valid response	212 (100.0%)
	Total missing	78

**Table 5.3.2** 



Question	Response	Number of Respondents (%)
Unhealthy days (physically or mentally unhealthy, max 30)	Any unhealthy days	151 (71.9%)
	1-5 unhealthy days	31 (14.8%)
	6-10 unhealthy days	23 (11.0%)
	11-20 unhealthy days	21 (10.0%)
	21-30 unhealthy days	76 (36.2%)
	No unhealthy days	59 (28.1%)
	Total valid response	210 (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	84 (51.2%)
	1-5 unhealthy days	29 (17.7%)
	6-10 unhealthy days	10 (6.1%)
	11-20 unhealthy days	22 (13.4%)
	21-30 unhealthy days	23 (14.0%)
	No unhealthy days	80 (48.8%)
	Total valid response	164 (100.0%)
	Total missing	126

# 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	140 (60.6%)

Question	Response	Number of Respondents (%)
	No	91 (39.4%)
	Total valid response	231 (100.0%)
	Total missing	59
Which impairment or health problem, if any, limits your activities?		
a) Arthritis/rheumatism	Yes	40 (34.5%)
	No	72 (62.1%)
	Don't know/Not sure	4 (3.4%)
	Total valid response	116 (100.0%)
	Total missing	174
b) Back or neck problem	Yes	77 (61.1%)
	No	45 (35.7%)
	Don't know/Not sure	3 (2.4%)
	Refused	1 (0.8%)
	Total valid response	126 (100.0%)
	Total missing	164
c) Fractures, bone/joint injury	Yes	30 (27.0%)
	No	78 (70.3%)
	Don't know/Not sure	2 (1.8%)
	Refused	1 (0.9%)
	Total valid response	111 (100.0%)
	Total missing	179
d) Walking problem	Yes	71 (59.7%)
	No	46 (38.7%)
	Don't know/Not sure	2 (1.7%)
	Total valid response	119 (100.0%)
	Total missing	171



Question	Response	Number of Respondents (%)
e) Lung/breathing problem	Yes	32 (28.3%)
	No	76 (67.3%)
	Don't know/Not sure	5 (4.4%)
	Total valid response	113 (100.0%)
	Total missing	177
f) Hearing problem	Yes	37 (31.6%)
	No	79 (67.5%)
	Don't know/Not sure	1 (0.9%)
	Total valid response	117 (100.0%)
	Total missing	173
g) Eye/vision problem	Yes	83 (64.3%)
	No	44 (34.1%)
	Don't know/Not sure	2 (1.6%)
	Total valid response	129 (100.0%)
	Total missing	161
h) Heart problem	Yes	31 (27.2%)
	No	78 (68.4%)
	Don't know/Not sure	4 (3.5%)
	Refused	1 (0.9%)
	Total valid response	114 (100.0%)
	Total missing	176
i) Stroke problem	Yes	6 (5.5%)
	No	102 (92.7%)
	Don't know/Not sure	2 (1.8%)
	Total valid response	110 (100.0%)
	Total missing	180

Question	Response	Number of Respondents (%)
j) Hypertension/high blood pressure	Yes	61 (49.6%)
	No	60 (48.8%)
	Don't know/Not sure	1 (0.8%)
	Refused	1 (0.8%)
	Total valid response	123 (100.0%)
	Total missing	167
k) Diabetes	Yes	129 (89.0%)
	No	16 (11.0%)
	Total valid response	145 (100.0%)
	Total missing	145
I) Cancer	Yes	5 (4.5%)
	No	100 (90.9%)
	Don't know/Not sure	3 (2.7%)
	Refused	2 (1.8%)
	Total valid response	110 (100.0%)
	Total missing	180
m) Mental or emotional health	Yes	30 (25.6%)
	No	75 (64.1%)
	Don't know/Not sure	10 (8.5%)
	Refused	2 (1.7%)
	Total valid response	117 (100.0%)
	Total missing	173

### PT 1.2

Analysis Sets	Number of Respondents (%)
All valid respondents	75 (100.0%)



Analysis Sets	Number of Respondents (%)
Included in Provider Analysis Set (PAS)	75 (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	75
Included in the Eye Care Professional Set (Eye Specialist)	16 (21.3%)
Excluded in the Eye Care Professional Set (Eye Specialist)	59 (78.7%)
Reasons for exclusion from Eye Care Professional Set:	
Missing required speciality	59
No valid (non-missing) response for the supplemental eye questionnaire	0

#### PT 1.3

Subgroups	Number of Respondents (%)
Provider Analysis Set	75 (100.0%)
Primary Care Provider	7 (9.3%)
Diabetes Specialist Provider	39 (52.0%)
Eye Care Professional	16 (21.3%)
Ophthalmologist	10 (13.3%)

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

#### PT 1.4

Item	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
What is your specialty?	General primary care/Family practitioner	7 (100.0%)	2 (5.1%)	0 (0.0%)	9 (12.0%)
	Diabetes specialist	0 (0.0%)	39 (100.0%)	0 (0.0%)	39 (52.0%)
	General ophthalmologist	0 (0.0%)	0 (0.0%)	5 (50.0%)	5 (6.7%)
	Optometrist	0 (0.0%)	0 (0.0%)	0 (0.0%)	6 (8.0%)
	Retinal specialist	0 (0.0%)	0 (0.0%)	7 (70.0%)	7 (9.3%)

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

Item	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Nurse	0 (0.0%)	0 (0.0%)	0 (0.0%)	3 (4.0%)
	Health educator	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (2.7%)
	None of the above	0 (0.0%)	0 (0.0%)	0 (0.0%)	8 (10.7%)
	Total valid response	7 (100.0%)	39 (100.0%)	10 (100.0%)	75 (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)	7	39	10	75
	Mean	28.0	19.6	15.6	19.8
	SD	24.8	9.7	14.6	13.5
	Median	23.0	20.0	9.5	18.0
	Min.	8	0	2	0
	Max.	80	40	50	80
	Total missing	0	0	0	0

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
What is your main practice setting?	Diabetes clinic/practice	0 (0.0%)	16 (42.1%)	0 (0.0%)	20 (29.9%)
	Eye clinic/practice	0 (0.0%)	0 (0.0%)	5 (55.6%)	6 (9.0%)
	General medical clinic/practice	5 (83.3%)	4 (10.5%)	0 (0.0%)	10 (14.9%)
	Hospital	1 (16.7%)	17 (44.7%)	3 (33.3%)	25 (37.3%)
	Other	0 (0.0%)	1 (2.6%)	1 (11.1%)	6 (9.0%)
	Total Valid Response	6 (100.0%)	38 (100.0%)	9 (100.0%)	67 (100.0%)



Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Total missing	1	1	1	8

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Where is your main practice located?	Urban setting	6 (100.0%)	29 (78.4%)	8 (88.9%)	51 (77.3%)
	Non-urban setting	0 (0.0%)	8 (21.6%)	1 (11.1%)	15 (22.7%)
	Total Valid Response	6 (100.0%)	37 (100.0%)	9 (100.0%)	66 (100.0%)
	Total missing	1	2	1	9

### PT 2.3

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
In which sector is your main practice?	Government	1 (16.7%)	10 (27.0%)	4 (44.4%)	17 (26.2%)
	Private	2 (33.3%)	13 (35.1%)	2 (22.2%)	26 (40.0%)
	Non profit	1 (16.7%)	7 (18.9%)	1 (11.1%)	11 (16.9%)
	Combined/mixed	2 (33.3%)	7 (18.9%)	2 (22.2%)	11 (16.9%)
	Total Valid Response	6 (100.0%)	37 (100.0%)	9 (100.0%)	65 (100.0%)
	Total missing	1	2	1	10

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Is your main practice limited to	No	6 (100.0%)	28 (75.7%)	8 (88.9%)	56 (84.8%)

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
certain populations?					
	Yes, limited by age	0 (0.0%)	7 (18.9%)	0 (0.0%)	7 (10.6%)
	Yes, limited to persons with health insurance	0 (0.0%)	2 (5.4%)	1 (11.1%)	3 (4.5%)
	Total valid response	6 (100.0%)	37 (100.0%)	9 (100.0%)	66 (100.0%)
	Total missing	1	2	1	9

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	5 (100.0%)	8 (25.8%)	0 (0.0%)	17 (29.8%)
	More than 1 week but less than 1 month	0 (0.0%)	11 (35.5%)	3 (33.3%)	19 (33.3%)
	More than 1 month but less than 2 months	0 (0.0%)	3 (9.7%)	2 (22.2%)	5 (8.8%)
	More than 2 months but less than 3 months	0 (0.0%)	2 (6.5%)	0 (0.0%)	3 (5.3%)
	More than 3 months but less than 6 months	0 (0.0%)	3 (9.7%)	1 (11.1%)	4 (7.0%)
	Do not take appointments	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (3.5%)
	Other	0 (0.0%)	4 (12.9%)	0 (0.0%)	4 (7.0%)
	Don't know/Not sure	0 (0.0%)	0 (0.0%)	3 (33.3%)	3 (5.3%)
	Total Valid Response	5 (100.0%)	31 (100.0%)	9 (100.0%)	57 (100.0%)
	Total missing	2	8	1	18



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)	5	28	8	51
	Mean	255	132.9	168.6	151.7
	SD	154.5	155.4	171.6	177.4
	Median	200	90	112.5	90
	Min.	100	8	4	3
	Max.	500	700	500	700
	Total missing	2	11	2	24
What percentage of the patients in your main practice have diabetes [% patients]	Total valid response (n)	5	29	8	53
	Mean	14.8	73.5	16.3	52.1
	SD	4.8	31.4	10.9	38.1
	Median	12	85	12.5	50
	Min.	10	5	5	1
	Max.	20	100	40	100
	Total missing	2	10	2	22

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	3 (60.0%)	4 (12.9%)	2 (25.0%)	13 (23.2%)
	Pay a reduced/subsidized rate	0 (0.0%)	0 (0.0%)	1 (12.5%)	1 (1.8%)
	Pay out-of-pocket	0 (0.0%)	1 (3.2%)	1 (12.5%)	4 (7.1%)

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	(full fees)				
	Pay through insurance	2 (40.0%)	27 (87.1%)	4 (50.0%)	38 (67.9%)
	Patient pays some, insurance pays some	0 (0.0%)	1 (3.2%)	1 (12.5%)	3 (5.4%)
	Total valid response	5 (100.0%)	31 (100.0%)	8 (100.0%)	56 (100.0%)
	Total missing	2	8	2	19

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 (20.0%)	6 (19.4%)		9 (15.5%)
	No	4 (80.0%)	25 (80.6%)	9 (100.0%)	49 (84.5%)
	Total valid response	5 (100.0%)	31 (100.0%)	9 (100.0%)	58 (100.0%)
	Total missing	2	8	1	17
In which other practice setting(s) do you work?	General medical clinic/practice		1 (20.0%)		1 (12.5%)
	Diabetes clinic/practice		3 (60.0%)		3 (37.5%)
	Other	1 (100.0%)	2 (40.0%)		5 (62.5%)
	Total valid response	1 (100.0%)	5 (100.0%)		8 (100.0%)
	Total missing	6	34	10	67
In which sector(s) is(are) the practice(s)?	Private		2 (40.0%)		2 (25.0%)
	Non profit	1 (100.0%)	1 (20.0%)		3 (37.5%)
	Combined/mixed		2 (40.0%)		3



Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
					(37.5%)
	Total valid response	1 (100.0%)	5 (100.0%)		8 (100.0%)
	Total missing	6	34	10	67
Is there a major difference between your practices with respect to how diabetic eye disease is screened and managed?	Yes	1 (100.0%)	2 (40.0%)		3 (37.5%)
	No		3 (60.0%)		5 (62.5%)
	Total valid response	1 (100.0%)	5 (100.0%)		8 (100.0%)
	Total missing	6	34	10	67

Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Blood glucose	Yes		5 (100.0%)	30 (100.0%)	5 (62.5%)	50 (92.6%)
		Total valid numeric response (n)	4 (80.0%)	27 (90.0%)	5 (62.5%)	44 (81.5%)
		Mean	274.3	145.0	3.4	125.8
		SD	181.5	175.9	1.9	168.8
		Median	365.0	5.0	4.0	4.0
		Min	2	0	1	0
		Max	365	365	6	365
		Total missing	3	12	5	31
	No			<b>!</b>	3 (37.5%)	4 (7.4%)
	Total valid response		5 (100.0%)	30 (100.0%)	8 (100.0%)	54 (100.0%)
	Total		2	9	2	21

Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	missing					
HbA1c	Yes		4 (100.0%)	30 (100.0%)	5 (62.5%)	48 (90.6%)
		Total valid numeric response (n)	3 (75.0%)	27 (90.0%)	5 (62.5%)	43 (81.1%)
		Mean	244.0	118.7	1.4	100.8
		SD	209.6	167.1	0.9	159.6
		Median	365.0	4.0	2.0	4.0
		Min	2	0	0	0
		Max	365	365	2	365
		Total missing	4	12	5	32
	No				3 (37.5%)	5 (9.4%)
	Total valid response		4 (100.0%)	30 (100.0%)	8 (100.0%)	53 (100.0%)
	Total missing	-	3	9	2	22
Urine check	Yes		5 (100.0%)	30 (100.0%)	3 (50.0%)	46 (90.2%)
		Total valid numeric response (n)	4 (80.0%)	28 (93.3%)	3 (50.0%)	42 (82.4%)
		Mean	257.8	126.1	5.0	119.3
		SD	173.9	171.1	4.6	166.1
		Median	332.5	4.0	4.0	4.0
		Min	1	0	1	0
		Max	365	365	10	365
		Total missing	3	11	7	33
	No		•		3 (50.0%)	5 (9.8%)
	Total valid response		5 (100.0%)	30 (100.0%)	6 (100.0%)	51 (100.0%)
	Total missing		2	9	4	24



Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Weight check	Yes		4 (100.0%)	30 (100.0%)	4 (57.1%)	46 (90.2%)
	,	Total valid numeric response (n)	3 (75.0%)	28 (93.3%)	4 (57.1%)	42 (82.4%)
		Mean	244.7	113.9	2.8	103.9
		SD	208.4	165.9	1.5	160.4
		Median	365.0	4.0	3.0	4.0
		Min	4	0	1	0
		Max	365	365	4	365
		Total missing	4	11	6	33
	No			I	3 (42.9%)	5 (9.8%)
	Total valid response		4 (100.0%)	30 (100.0%)	7 (100.0%)	51 (100.0%)
	Total missing		3	9	3	24
Blood pressure check	Yes		5 (100.0%)	30 (100.0%)	7 (100.0%)	52 (98.1%)
	,	Total valid numeric response (n)	4 (80.0%)	28 (93.3%)	7 (100.0%)	48 (90.6%)
		Mean	274.8	127.0	8.0	113.8
		SD	180.5	170.8	10.2	165.3
		Median	365.0	4.0	4.0	4.0
		Min	4	0	1	0
		Max	365	365	30	365
		Total missing	3	11	3	27
	No			I	ı	1 (1.9%)
	Total valid response		5 (100.0%)	30 (100.0%)	7 (100.0%)	53 (100.0%)
	Total missing		2	9	3	22
Foot check	Yes		4	30	2 (33.3%)	44

Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
			(100.0%)	(100.0%)		(86.3%)
		Total valid numeric response (n)	3 (75.0%)	28 (93.3%)	2 (33.3%)	40 (78.4%)
		Mean	67.0	113.7	7.0	96.8
		SD	75.9	161.6	4.2	148.6
		Median	50.0	4.0	7.0	4.0
		Min	1	0	4	0
		Max	150	365	10	365
		Total missing	4	11	8	35
	No				4 (66.7%)	7 (13.7%)
	Total valid response		4 (100.0%)	30 (100.0%)	6 (100.0%)	51 (100.0%)
	Total missing		3	9	4	24
Eye examination - Un-dilated	Yes		1 (25.0%)	5 (16.7%)	7 (87.5%)	17 (32.1%)
		Total valid numeric response (n)	1 (25.0%)	5 (16.7%)	7 (87.5%)	17 (32.1%)
		Mean	1.0	74.6	45.9	62.5
		SD		162.3	112.1	134.7
		Median	1.0	1.0	4.0	1.0
		Min	1	1	0	0
		Max	1	365	300	365
		Total missing	6	34	3	58
	No		3 (75.0%)	25 (83.3%)	1 (12.5%)	36 (67.9%)
	Total valid response		4 (100.0%)	30 (100.0%)	8 (100.0%)	53 (100.0%)
	Total		3	9	2	22



Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	missing					
Eye examination - Optical Coherence Tomography	Yes			1 (3.3%)	8 (88.9%)	12 (23.1%)
		Total valid numeric response (n)	0 (0.0%)	1 (3.3%)	8 (88.9%)	12 (23.1%)
		Mean		1.0	47.0	62.0
		SD			128.5	141.5
		Median		1.0	1.0	1.0
		Min		1	0	0
		Max		1	365	365
		Total missing	7	38	2	63
	No		4 (100.0%)	29 (96.7%)	1 (11.1%)	40 (76.9%)
	Total valid response		4 (100.0%)	30 (100.0%)	9 (100.0%)	52 (100.0%)
	Total missing		3	9	1	23
Eye examination - Fundoscopy	Yes		1 (25.0%)	2 (6.7%)	8 (88.9%)	12 (22.6%)
		Total valid numeric response (n)	1 (25.0%)	2 (6.7%)	8 (88.9%)	12 (22.6%)
		Mean	1.0	2.5	85.0	57.2
		SD		3.5	153.8	129.4
		Median	1.0	2.5	4.0	3.0
		Min	1	0	0	0
		Max	1	5	365	365
		Total missing	6	37	2	63
	No		3 (75.0%)	28 (93.3%)	1 (11.1%)	41 (77.4%)

Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Total valid response		4 (100.0%)	30 (100.0%)	9 (100.0%)	53 (100.0%)
	Total missing		3	9	1	22
Eye examination - Fluorescein Angiography	Yes			3 (10.0%)	8 (88.9%)	12 (23.1%)
		Total valid numeric response (n)	0 (0.0%)	3 (10.0%)	8 (88.9%)	12 (23.1%)
		Mean		122.3	84.9	87.3
		SD		210.2	153.8	155.3
		Median		1.0	4.0	2.5
		Min		1	0	0
		Max		365	365	365
		Total missing	7	36	2	63
	No		4 (100.0%)	27 (90.0%)	1 (11.1%)	40 (76.9%)
	Total valid response		4 (100.0%)	30 (100.0%)	9 (100.0%)	52 (100.0%)
	Total missing		3	9	1	23
Eye examination - Lipid check	Yes		1 (25.0%)	2 (6.7%)	7 (77.8%)	10 (19.2%)
	,	Total valid numeric response (n)	1 (25.0%)	1 (3.3%)	7 (77.8%)	9 (17.3%)
		Mean	1.0	5.0	60.4	47.7
		SD			135.5	120.1
		Median	1.0	5.0	2.0	2.0
		Min	1	5	0	0
		Max	1	5	365	365
		Total	6	38	3	66



Type of Test	Yes/No	How often/year	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
		missing				
	No		3 (75.0%)	28 (93.3%)	2 (22.2%)	42 (80.8%)
	Total valid response		4 (100.0%)	30 (100.0%)	9 (100.0%)	52 (100.0%)
	Total missing		3	9	1	23

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	3 (75.0%)	26 (96.3%)	5 (62.5%)	(82.4%)
	Diet/nutrition	3 (75.0%)	26 (96.3%)	1 (12.5%)	37 (72.5%)
	Exercise/physical activity	3 (75.0%)	26 (96.3%)	1 (12.5%)	38 (74.5%)
	Medicines	4 (100.0%)	25 (92.6%)	3 (37.5%)	40 (78.4%)
	Foot care and inspection	3 (75.0%)	19 (70.4%)	0 (0.0%)	28 (54.9%)
	Blood pressure	3 (75.0%)	25 (92.6%)	4 (50.0%)	39 (76.5%)
	Eye care and exams	3 (75.0%)	18 (66.7%)	7 (87.5%)	36 (70.6%)
	Lipid check	3 (75.0%)	24 (88.9%)	1 (12.5%)	34 (66.7%)
	Other	0 (0.0%)	2 (7.4%)	0 (0.0%)	4 (7.8%)
	None of the above	0 (0.0%)	1 (3.7%)	0 (0.0%)	1 (2.0%)
	Total valid response	4 (100.0%)	27 (100.0%)	8 (100.0%)	51 (100.0%)
	Total missing	3	12	2	24

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%)	9 (34.6%)	7 (87.5%)	23 (46.9%)
	Yes, but information on eye complications is not sufficient	1 (25.0%)	11 (42.3%)	1 (12.5%)	14 (28.6%)
	Yes, but no information on eye complications is included	0 (0.0%)	5 (19.2%)	0 (0.0%)	6 (12.2%)
	No written information is available for patients	1 (25.0%)	1 (3.8%)	0 (0.0%)	4 (8.2%)
	Don't know/Not sure	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (4.1%)
	Total Valid Response	4 (100.0%)	26 (100.0%)	8 (100.0%)	49 (100.0%)
	Total missing	3	13	2	26

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%)	25 (96.2%)	5 (62.5%)	42 (84.0%)
	Yes, available but not used by staff	0 (0.0%)	0 (0.0%)	1 (12.5%)	1 (2.0%)
	Not available	1 (25.0%)	0 (0.0%)	2 (25.0%)	6 (12.0%)
	Don't	0 (0.0%)	1 (3.8%)	0 (0.0%)	1 (2.0%)



Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	know/Not sure				
	Total Valid Response	4 (100.0%)	26 (100.0%)	8 (100.0%)	50 (100.0%)
	Total missing	3	13	2	25

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%)	13 (50.0%)	6 (75.0%)	27 (54.0%)
	Yes, available but not used by staff	0 (0.0%)	2 (7.7%)	0 (0.0%)	3 (6.0%)
	Not available	2 (50.0%)	9 (34.6%)	2 (25.0%)	17 (34.0%)
	Don't know/Not sure	0 (0.0%)	2 (7.7%)	0 (0.0%)	3 (6.0%)
	Total Valid Response	4 (100.0%)	26 (100.0%)	8 (100.0%)	50 (100.0%)
	Total missing	3	13	2	25

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	After a predetermined number of years (numeric response)	0 (0.0%)	7 (29.2%)	1 (14.3%)	10 (21.3%)

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
with diabetes - Type I?	(n)				
	Mean		4.9	1.0	4.5
	SD		0.9		1.4
	Median		5.0	1.0	5.0
	Min		3	1	1
	Max	-	6	1	6
	After a predetermined age (numeric response) (n)	0 (0.0%)	0 (0.0%)	1 (14.3%)	1 (2.1%)
	Mean			50.0	50.0
	SD				
	Median			50.0	50.0
	Min			50	50
	Max			50	50
	As soon as they are diagnosed	3 (75.0%)	15 (62.5%)	3 (42.9%)	28 (59.6%)
	When a patient reports eye/vision problems				1 (2.1%)
	No standard practice, timing varies case by case	1 (25.0%)	2 (8.3%)	1 (14.3%)	5 (10.6%)
	Don't know/Not sure			1 (14.3%)	2 (4.3%)
	Total valid response	4 (100.0%)	24 (100.0%)	7 (100.0%)	47 (100.0%)
	Total missing	3	15	3	28
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%)	1 (2.0%)
	Mean		•	•	1.0
	SD	1			



Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Median				1.0
	Min				1
	Max				1
	After a predetermined age (numeric response) (n)	0 (0.0%)	0 (0.0%)	1 (12.5%)	1 (2.0%)
	Mean		1	50.0	50.0
	SD				l
	Median			50.0	50.0
	Min			50	50
	Max			50	50
	As soon as they are diagnosed	3 (75.0%)	23 (88.5%)	5 (62.5%)	39 (78.0%)
	When a patient reports eye/vision problems		2 (7.7%)		4 (8.0%)
	No standard practice, timing varies case by case	1 (25.0%)	1 (3.8%)	2 (25.0%)	4 (8.0%)
	Don't know/Not sure		1	1	1 (2.0%)
	Total valid response	4 (100.0%)	26 (100.0%)	8 (100.0%)	50 (100.0%)
	Total missing	3	13	2	25

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%)	25 (96.2%)	5 (62.5%)	42 (84.0%)
	Every two years	1 (25.0%)	1 (3.8%)	1 (12.5%)	3 (6.0%)
	Only when	1 (25.0%)	0 (0.0%)	0 (0.0%)	1 (2.0%)

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	symptoms are present				
	Other	0 (0.0%)	0 (0.0%)	2 (25.0%)	2 (4.0%)
	Don't know/Not sure	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (4.0%)
	Total Valid Response	4 (100.0%)	26 (100.0%)	8 (100.0%)	50 (100.0%)
	Total missing	3	13	2	25

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Do you screen patients for DR?	Yes	1 (25.0%)	3 (11.5%)	6 (75.0%)	12 (23.5%)
	No	3 (75.0%)	23 (88.5%)	2 (25.0%)	39 (76.5%)
	Total valid response	4 (100.0%)	26 (100.0%)	8 (100.0%)	51 (100.0%)
	Total missing	3	13	2	24
Where do you screen patients?	In clinic	1 (100.0%)	1 (33.3%)	5 (100.0%)	9 (81.8%)
	Other		2 (66.7%)		2 (18.2%)
	Total valid response	1 (100.0%)	3 (100.0%)	5 (100.0%)	11 (100.0%)
	Total missing	6	36	5	64

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
What patient characteristics influence your vision care and/or vision referrals?	Diabetes duration	1 (25.0%)	14 (53.8%)	7 (100.0%)	26 (54.2%)
	Patient's age	1 (25.0%)	8 (30.8%)	5 (71.4%)	17



Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
					(35.4%)
	Patient's gender	0 (0.0%)	1 (3.8%)	1 (14.3%)	2 (4.2%)
	Presence of comorbidities such as hypertension, etc.	0 (0.0%)	10 (38.5%)	5 (71.4%)	18 (37.5%)
	High glucose levels	1 (25.0%)	7 (26.9%)	5 (71.4%)	18 (37.5%)
	Ability or inability to pay	0 (0.0%)	1 (3.8%)	0 (0.0%)	2 (4.2%)
	Insurance restrictions	0 (0.0%)	1 (3.8%)	0 (0.0%)	1 (2.1%)
	Patient adherence to recommendations	0 (0.0%)	1 (3.8%)	1 (14.3%)	2 (4.2%)
	None of the above	2 (50.0%)	11 (42.3%)	0 (0.0%)	17 (35.4%)
	Not applicable	1 (25.0%)	1 (3.8%)	0 (0.0%)	4 (8.3%)
	Total valid response	4 (100.0%)	26 (100.0%)	7 (100.0%)	48 (100.0%)
	Total missing	3	13	3	27

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
What are the major barriers to optimizing eye health faced by patients with diabetes in your main practice?	Cost of care	0 (0.0%)	3 (12.5%)	3 (50.0%)	6 (13.6%)
	Proximity to care	0 (0.0%)	2 (8.3%)	2 (33.3%)	5 (11.4%)
	Long wait time for appointment	1 (25.0%)	13 (54.2%)	1 (16.7%)	21 (47.7%)
	Long wait time on the day of visit	0 (0.0%)	2 (8.3%)	2 (33.3%)	6 (13.6%)
	Referral process	1 (25.0%)	4 (16.7%)	0 (0.0%)	5 (11.4%)

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	Recommended treatments are not available	0 (0.0%)	3 (12.5%)	0 (0.0%)	4 (9.1%)
	Lack of knowledge and/or awareness	0 (0.0%)	3 (12.5%)	3 (50.0%)	9 (20.5%)
	Patients fear of treatment/results	0 (0.0%)	3 (12.5%)	1 (16.7%)	4 (9.1%)
	Patients they are a burden on family/friends	0 (0.0%)	0 (0.0%)	1 (16.7%)	1 (2.3%)
	Limited access to diabetes specialists	0 (0.0%)	2 (8.3%)	1 (16.7%)	3 (6.8%)
	Limited access to eye specialists	1 (25.0%)	10 (41.7%)	1 (16.7%)	13 (29.5%)
	Patients feel eye complications are unlikely	1 (25.0%)	5 (20.8%)	2 (33.3%)	9 (20.5%)
	Patients feel eye exams are not important	1 (25.0%)	7 (29.2%)	2 (33.3%)	13 (29.5%)
	Patients have competing responsibilities and priorities	1 (25.0%)	3 (12.5%)	1 (16.7%)	7 (15.9%)
	Clinic too small or lack necessary equipment/staff	0 (0.0%)	4 (16.7%)	1 (16.7%)	5 (11.4%)
	Other	1 (25.0%)	1 (4.2%)	0 (0.0%)	4 (9.1%)
	Total valid response	4 (100.0%)	24 (100.0%)	6 (100.0%)	44 (100.0%)
	Total missing	3	15	4	31

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	1 (25.0%)	14 (53.8%)	4 (50.0%)	23 (46.9%)



Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
	No	3 (75.0%)	10 (38.5%)	4 (50.0%)	24 (49.0%)
	Don't know/Not sure	0 (0.0%)	2 (7.7%)	0 (0.0%)	2 (4.1%)
	Total Valid Response	4 (100.0%)	26 (100.0%)	8 (100.0%)	49 (100.0%)
	Total missing	3	13	2	26

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Do you share relevant patient information with other health care professionals involved in the patients care e.g. his or her general practitioner, ophthalmologist, podiastrist?	Yes	2 (50.0%)	24 (92.3%)	8 (100.0%)	42 (85.7%)
	No	2 (50.0%)	1 (3.8%)	0 (0.0%)	6 (12.2%)
	Don't know/Not sure	0 (0.0%)	1 (3.8%)	0 (0.0%)	1 (2.0%)
	Total Valid Response	4 (100.0%)	26 (100.0%)	8 (100.0%)	49 (100.0%)
	Total missing	3	13	2	26

# PT 3.1

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
Please indicate your age:	18 - 29			1 (14.3%)	3 (6.3%)
	30 - 39		3 (11.5%)	1 (14.3%)	5 (10.4%)
	40 - 49		5 (19.2%)	2 (28.6%)	10

Question	Response	Primary Care Provider	Diabetes Specialist Provider	Ophthalmologist	PAS
					(20.8%)
	50 - 59	4 (100.0%)	12 (46.2%)	3 (42.9%)	22 (45.8%)
	60 - 69		6 (23.1%)		8 (16.7%)
	Total valid response	4 (100.0%)	26 (100.0%)	7 (100.0%)	48 (100.0%)
	Total missing	3	13	3	27
What is your gender?	Female	1 (25.0%)	12 (46.2%)		20 (41.7%)
	Male	3 (75.0%)	14 (53.8%)	7 (100.0%)	28 (58.3%)
	Total valid response	4 (100.0%)	26 (100.0%)	7 (100.0%)	48 (100.0%)
	Total missing	3	13	3	27
What is your highest level of education completed?	Secondary School		1 (3.8%)		5 (10.4%)
	College/University		5 (19.2%)	1 (14.3%)	9 (18.8%)
	Graduate or advanced degree (e.g. PhD, MD, etc)	4 (100.0%)	20 (76.9%)	6 (85.7%)	34 (70.8%)
	Total valid response	4 (100.0%)	26 (100.0%)	7 (100.0%)	48 (100.0%)
	Total missing	3	13	3	27

Question	Response	Ophthalmologist
What percentage of your patients have diabetic retinopathy	Total valid numeric response (n)	8
	Mean	15.4
	SD	13.6
	Median	10.0
	Min	0
	Max	40



Question	Response	Ophthalmologist
	Total missing	2

Question	Response	Ophthalmologist
What percentage of your patients have diabetic macular edema?	Total valid numeric response (n)	8
	Mean	10.5
	SD	7.4
	Median	10.0
	Min	0
	Max	20
	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?	More than 1 week but less than 1 month	4 (57.1%)
	More than 1 month but less than 2 months	2 (28.6%)
	Do not take appointment	0 (0.0%)
	Don't know/Not sure	1 (14.3%)
	Total Valid Response	7 (100.0%)
	Total missing	3

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 (14.3%)
	More than 1 week but less than 1 month	1 (14.3%)
	Other	0 (0.0%)
	Don't know/Not sure	0 (0.0%)
	There is not wait, diagnosis	5 (71.4%)

Question	Response	Ophthalmologist
	is given when screened	
	Total Valid Response	7 (100.0%)
	Total missing	3

Type of Treatment	Question	Response/time	Ophthalmologist
Laser photocoagulation	Is the treatment available?	Available within country	2 (28.6%)
		Available locally	2 (28.6%)
		Available in practice	7 (100.0%)
		Not available	
		Total valid response	7 (100.0%)
		Total missing	3
	What is the average amount of time your patients wait for a consultation appointment? (weeks)	Total valid numeric response (n)	4 (66.7%)
		Mean	2.8
		SD	1.5
		Median	3.0
		Min	1
		Max	4
		Don't know/not sure	2 (33.3%)
		Total valid response	6 (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)	4 (66.7%)
		Mean	2.5
		SD	1.3
		Median	2.5
		Min	1
		Max	4



Type of Treatment	Question	Response/time	Ophthalmologist
		Don't know/not sure	1 (16.7%)
		Not applicable	1 (16.7%)
		Total valid response	6 (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)	3 (75.0%)
		Mean	1.7
		SD	0.6
		Median	2.0
		Min	1
		Max	2
		Not applicable	1 (25.0%)
		Total valid response	4 (100.0%)
		Total missing	6
Anti-VEGF therapies	Is the treatment available?	Available within country	2 (28.6%)
		Available locally	2 (28.6%)
		Available in practice	7 (100.0%)
		Not available	
		Total valid response	7 (100.0%)
		Total missing	3
	What is the average amount of time your patients wait for a consultation appointment? (weeks)	Total valid numeric response (n)	5 (83.3%)
		Mean	3.0
		SD	1.0
		Median	3.0
		Min	2
		Max	4
		Don't know/not sure	1 (16.7%)

Type of Treatment	Question	Response/time	Ophthalmologist
		Total valid response	6 (100.0%)
		Total missing	4
	What is the average amount of time your patients wait for a first treatment?(weeks)	Total valid numeric response (n)	6 (100.0%)
		Mean	2.8
		SD	1.0
		Median	2.5
		Min	2
		Max	4
		Don't know/not sure	
		Total valid response	6 (100.0%)
		Total missing	4
	What is the average amount of time your patients wait for a second treatment?(weeks)	Total valid numeric response (n)	5 (100.0%)
		Mean	3.6
		SD	0.9
		Median	4.0
		Min	2
		Max	4
		Total valid response	5 (100.0%)
		Total missing	5
Intravitreal steroid	Is the treatment available?	Available within country	2 (28.6%)
		Available locally	2 (28.6%)
		Available in practice	7 (100.0%)
		Not available	
		Total valid response	7 (100.0%)
		Total missing	3
	What is the average amount of time your patients wait for a consultation	Total valid numeric	4 (66.7%)



Type of Treatment	Question	Response/time	Ophthalmologist
	appointment? (weeks)	response (n)	
		Mean	2.8
		SD	1.0
		Median	2.5
		Min	2
		Max	4
		Don't know/not sure	2 (33.3%)
		Total valid response	6 (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)	4 (80.0%)
		Mean	2.8
		SD	1.0
		Median	2.5
		Min	2
		Max	4
		Don't know/not sure	1 (20.0%)
		Total valid response	5 (100.0%)
		Total missing	5
	What is the average amount of time your patients wait for a second treatment?(weeks)	Total valid numeric response (n)	4 (100.0%)
		Mean	9.5
		SD	5.0
		Median	12.0
		Min	2
		Max	12
		Total valid response	4 (100.0%)
		Total missing	6
Uncomplicated vitrectomy	Is the treatment available?	Available within country	2 (33.3%)

Type of Treatment	Question	Response/time	Ophthalmologist
		Available locally	2 (33.3%)
		Available in practice	6 (100.0%)
		Not available	
		Total valid response	6 (100.0%)
		Total missing	4
	What is the average amount of time your patients wait for a consultation appointment? (weeks)	Total valid numeric response (n)	3 (60.0%)
		Mean	4.0
		SD	0.0
		Median	4.0
		Min	4
		Max	4
		Don't know/not sure	2 (40.0%)
		Total valid response	5 (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)	5 (83.3%)
		Mean	3.6
		SD	0.9
		Median	4.0
		Min	2
		Max	4
		Don't know/not sure	1 (16.7%)
		Total valid response	6 (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 (50.0%)
		Mean	2.5



SD	Type of Treatment	Question	Response/time	Ophthalmologist
Min   2			SD	0.7
Max   3     Don't know/not sure   1 (25.0%)     Total valid response   7 (100.0%)     Total missing   6     Available within country   2 (28.6%)     Available locally   2 (28.6%)     Available in practice   7 (100.0%)     Total valid response   7 (100.0%)     Total valid numeric response (n)     What is the average amount of time your patients wait for a consultation appointment? (weeks)   Mean   4.0     Min			Median	2.5
Don't know/not sure   1 (25.0%)			Min	2
Not applicable   1 (25.0%)   Total valid response   Total missing   6			Max	3
Total valid response			1	1 (25.0%)
Total missing   6			Not applicable	1 (25.0%)
State treatment available?   Available within country   2 (28.6%)				4 (100.0%)
retinal surgery         country         Available locally         2 (28.6%)           Available in practice         7 (100.0%)         7 (100.0%)           Not available         Total valid response         7 (100.0%)           Total missing         3         3           What is the average amount of time your patients wait for a consultation appointment? (weeks)         Total valid numeric response (n)         4 (66.7%)           Mean         4.0         5D         0.0           Median         4.0         Mean         4.0           Min         4         Max         4         Don't know/not sure         2 (33.3%)           Total valid response         Total valid response         6 (100.0%)         Total valid numeric response (n)         5 (83.3%)           What is the average amount of time your patients wait for a first treatment?(weeks)         Total valid numeric response (n)         5 (83.3%)			Total missing	6
Available in practice		Is the treatment available?		2 (28.6%)
practice Not available Total valid response Total missing  What is the average amount of time your patients wait for a consultation appointment? (weeks)  Mean 4.0  SD 0.0  Median 4.0  Min 4  Max 4  Don't know/not sure  Total valid response Total valid response  Total valid response  Total valid response  Total valid response  Total valid response  Total valid response  Total valid response  Total valid response  Total valid response  Total valid response  Total valid numeric response  Total valid numeric response  Total valid numeric response (n)  What is the average amount of time your patients wait for a first treatment?(weeks)  Mean 4.0			Available locally	2 (28.6%)
Total valid response  Total missing  3  What is the average amount of time your patients wait for a consultation appointment? (weeks)  Mean  4.0  SD  0.0  Median  4.0  Min  4  Max  4  Don't know/not sure  Total valid response  Total valid numeric response  Total valid numeric response  Total valid numeric response  Total valid numeric response (n)  What is the average amount of time your patients wait for a first treatment? (weeks)  Mean  4.0				7 (100.0%)
response Total missing  3  What is the average amount of time your patients wait for a consultation appointment? (weeks)  Mean 4.0  SD 0.0  Median 4.0  Min 4  Max 4  Don't know/not sure  Total valid response  Total valid numeric response  Total missing 4  What is the average amount of time your patients wait for a first treatment? (weeks)  Mean 4.0			Not available	
What is the average amount of time your patients wait for a consultation appointment? (weeks)  Mean  4.0  SD  0.0  Median  4.0  Min  4  Max  4  Don't know/not sure  Total valid response  Total valid response  Total valid response  Total valid response  Total valid numeric response  Total valid response  Total valid response  Total valid numeric response (n)  What is the average amount of time your patients wait for a first treatment?(weeks)  Mean  4 (66.7%)  For all valid numeric response (n)  Total valid numeric response (n)				7 (100.0%)
your patients wait for a consultation appointment? (weeks)  Mean 4.0  SD 0.0  Median 4.0  Min 4  Max 4  Don't know/not sure  Total valid response  Total missing 4  What is the average amount of time your patients wait for a first treatment? (weeks)  Mean 4.0  Min 4  Max 4  Don't know/not sure  Total valid response  Total wait of time response (n)  Mean 4.0			Total missing	3
SD 0.0  Median 4.0  Min 4  Max 4  Don't know/not sure  Total valid response  Total missing 4  What is the average amount of time your patients wait for a first treatment?(weeks)  Total valid numeric response (n)  Total valid numeric response (n)  Mean 4.0		your patients wait for a consultation		4 (66.7%)
Median         4.0           Min         4           Max         4           Don't know/not sure         2 (33.3%)           Total valid response         6 (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)         5 (83.3%)           Mean         4.0			Mean	4.0
Min 4  Max 4  Don't know/not sure  Total valid response  Total missing 4  What is the average amount of time your patients wait for a first treatment?(weeks)  Mean 4.0			SD	0.0
Max 4  Don't know/not sure  Total valid response  Total missing 4  What is the average amount of time your patients wait for a first treatment?(weeks)  Mean 4.0			Median	4.0
Don't know/not sure  Total valid response  Total missing  What is the average amount of time your patients wait for a first treatment?(weeks)  Total valid numeric response (n)  Mean  4.0			Min	4
sure  Total valid response  Total missing 4  What is the average amount of time your patients wait for a first treatment?(weeks)  Mean 4.0			Max	4
response  Total missing 4  What is the average amount of time your patients wait for a first treatment?(weeks)  Mean 4.0			· ·	2 (33.3%)
What is the average amount of time your patients wait for a first treatment?(weeks)  Total valid numeric response (n)  Mean  4.0				6 (100.0%)
your patients wait for a first response (n) treatment?(weeks)  Mean 4.0			Total missing	4
		your patients wait for a first		5 (83.3%)
SD 1.4			Mean	4.0
			SD	1.4

Type of Treatment	Question	Response/time	Ophthalmologist
		Median	4.0
		Min	2
		Max	6
		Don't know/not sure	1 (16.7%)
		Total valid response	6 (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 (50.0%)
		Mean	3.0
		SD	1.4
		Median	3.0
		Min	2
		Max	4
		Don't know/not sure	1 (25.0%)
		Not applicable	1 (25.0%)
		Total valid response	4 (100.0%)
		Total missing	6

Question	Response	Ophthalmologist
Do you personally administer treatment for diabetic retinopathy?	Yes	6 (85.7%)
	No	1 (14.3%)
	Total valid response	7 (100.0%)
	Total missing	3
Who administer it?	Another provider in your practice	1 (100.0%)
	Refer to a provider at another facility	
	Total valid response	1 (100.0%)
	Total missing	9



Question	Response	Ophthalmologist
Do any of the following influence how you treat diabetic retinopathy or diabetic macular edema?	Diabetes duration	2 (40.0%)
	Patient's age	2 (40.0%)
	Presence of comorbidities such as hypertension, etc.	3 (60.0%)
	High glucose levels	2 (40.0%)
	Ability or inability to pay	1 (20.0%)
	Insurance restrictions	1 (20.0%)
	Patient educational level	1 (20.0%)
	Patient adherence to recommendations	2 (40.0%)
	None of the above	2 (40.0%)
	Total valid response	5 (100.0%)
	Total missing	5

### PT 4.8

Question	Response	Ophthalmologist
Do you treat diabetic retinopathy and diabetic macular edema based on:	Visual outcome	1 (16.7%)
	Both	5 (83.3%)
	Other	0 (0.0%)
	Total Valid Response	6 (100.0%)
	Total missing	4

Question	Response	Ophthalmologist
How are your patients with diabetes screened for diabetic eye disease?	Fundoscopy undilated	1 (16.7%)
	Fundoscopy dilated	6 (100.0%)
	Retinal photo	1 (16.7%)
	Optical Coherence Tomography	5 (83.3%)
	Fluorescein Angiography	3 (50.0%)

Question	Response	Ophthalmologist
	Other	1 (16.7%)
	Total valid response	6 (100.0%)
	Total missing	4

Question	Response	Ophthalmologist
In your opinion, do the majority of your patients present:	In time for screening	1 (16.7%)
	When visual problems have already occurred	5 (83.3%)
	Total Valid Response	6 (100.0%)
	Total missing	4

### 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	4 (66.7%)
	No	2 (33.3%)
	Total valid response	6 (100.0%)
	Total missing	4
If yes, When was your last training?	Greater than 1 year ago but less than 5 years	1 (25.0%)
	Within the past year	3 (75.0%)
	Total valid response	4 (100.0%)
	Total missing	6

Question	Response	Ophthalmologist
Would you be interested in online education and certification on DME, Angiogenesis and Anti-VEGF therapies?	Yes	3 (50.0%)
	No	3 (50.0%)
	Total Valid Response	6 (100.0%)
	Total missing	4



Question	Response	Ophthalmologist
How is outreach for screening for diabetic eye disease done in your main practice?	Health fairs for all	1 (16.7%)
	Health fairs for people with diabetes	1 (16.7%)
	At vision centers	3 (50.0%)
	Other	1 (16.7%)
	Not done	1 (16.7%)
	Don't know/Not sure	1 (16.7%)
	Total valid response	6 (100.0%)
	Total missing	4

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

Question	Response	Without DED (%)	With DED (%)	With DME (%)
Which of the following complications of diabetes do you have?	Amputation	1 (0.6%)	1 (1.7%)	1 (2.5%)
	Cardiovascular disease/Stroke	16 (10.1%)	16 (26.7%)	7 (17.5%)
	Foot ulcers	2 (1.3%)	1 (1.7%)	1 (2.5%)
	Irritable bowel disease	23 (14.5%)	8 (13.3%)	4 (10.0%)
	Kidney disease	6 (3.8%)	5 (8.3%)	6 (15.0%)
	Loss of feeling in hands or toes (neuropathy)	16 (10.1%)	23 (38.3%)	19 (47.5%)
	Vision loss	13 (8.2%)	31 (51.7%)	24 (60.0%)
	Broken bones or fractures	0 (0.0%)	2 (3.3%)	1 (2.5%)
	Other	7 (4.4%)	7 (11.7%)	2 (5.0%)
	None	103 (64.8%)	12 (20.0%)	3 (7.5%)
	Don't know/Not sure	4 (2.5%)	0 (0.0%)	1 (2.5%)
	Total Valid Response	159 (100.0%)	60 (100.0%)	40 (100.0%)
	Total missing	29	2	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".

Limitations	Without DED n (%)	With DED n (%)	With DME n (%)
Limited in any way in any activities because of impairment or health problem	66 (44.3%)	43 (71.7%)	31 (77.5%)
Impairment or health problem			
Diabetes	64 (86.5%)	35 (87.5%)	30 (96.8%)
Back or neck problem	40 (58.8%)	22 (66.7%)	15 (60.0%)
Walking problem	32 (53.3%)	23 (67.6%)	16 (64.0%)
Hypertension/high blood pressure	33 (50.0%)	13 (38.2%)	15 (65.2%)
Eye/vision problem	26 (40.6%)	30 (83.3%)	27 (93.1%)
Arthritis/rheumatism	19 (30.6%)	14 (43.8%)	7 (31.8%)
Hearing problem	16 (26.2%)	10 (31.3%)	11 (45.8%)

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

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



Limitations	Without DED n (%)	With DED n (%)	With DME n (%)
Fractures, bone/joint injury	14 (24.1%)	9 (28.1%)	7 (33.3%)
Lung/breathing problem	14 (23.7%)	9 (29.0%)	9 (39.1%)
Mental or emotional health	14 (23.0%)	10 (31.3%)	6 (25.0%)
Heart problem	11 (18.6%)	13 (38.2%)	7 (33.3%)
Stroke problem	4 (6.9%)	2 (6.5%)	0 (0.0%)
Cancer	1 (1.8%)	2 (6.3%)	2 (9.5%)

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

#### EXP 3

Health Status	Without DED (%)	With DED (%)	With DME (%)
Self-rated health: Good	86 (59.7%)	23 (39.0%)	15 (39.5%)
Self-rated health: Poor	58 (40.3%)	36 (61.0%)	23 (60.5%)
Physically unhealthy days	69 (57.5%)	37 (74.0%)	25 (73.5%)
Mentally unhealthy days	58 (45.3%)	27 (55.1%)	21 (60.0%)
Unhealthy days	84 (67.7%)	41 (78.8%)	26 (76.5%)
Activity limitation days	48 (50.5%)	22 (55.0%)	14 (48.3%)

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

Item	Response	All respondents	Respondents with Type I diabetes	Respondents with Type II diabetes
How do you manage your diabetes?	Diet	136 (48.7%)	51 (30.4%)	82 (76.6%)
	Oral medicine	83 (29.7%)	3 (1.8%)	78 (72.9%)
	Exercise	98 (35.1%)	42 (25.0%)	56 (52.3%)
	Insulin	217 (77.8%)	166 (98.8%)	50 (46.7%)
	Natural/Herbal medicine	4 (1.4%)	1 (0.6%)	3 (2.8%)
	Other	1 (0.4%)		1 (0.9%)
	None of the above	2 (0.7%)		2 (1.9%)

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

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

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

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

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

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

**EXP 5.1** 

Item	Response	Without DED (%)	With DED (%)	With DME (%)
Are you currently working?	Working for pay	81 (54.7%)	19 (31.7%)	12 (30.0%)
	Working without pay at home (e.g. housework, farming)	4 (2.7%)	0 (0.0%)	1 (2.5%)
	Volunteering	2 (1.4%)	5 (8.3%)	0 (0.0%)
	Retired	40 (27.0%)	29 (48.3%)	26 (65.0%)
	Student	10 (6.8%)	0 (0.0%)	0 (0.0%)
	Not working	11 (7.4%)	7 (11.7%)	1 (2.5%)
	Total Valid Response	148 (100.0%)	60 (100.0%)	40 (100.0%)
	Total missing	40	2	0
Do you receive assistance from the government?	Income assistance	4 (2.9%)	6 (10.3%)	2 (5.6%)
	Medical assistance	3 (2.1%)	0 (0.0%)	3 (8.3%)
	Food assistance	2 (1.4%)	0 (0.0%)	0 (0.0%)
	Housing assistance	3 (2.1%)	4 (6.9%)	0 (0.0%)
	Pension assistance	4 (2.9%)	3 (5.2%)	4 (11.1%)
	None of the above	126 (90.0%)	48 (82.8%)	27 (75.0%)
	Total valid response	140 (100.0%)	58 (100.0%)	36 (100.0%)
	Total missing	48	4	4
Did you have trouble paying for food at anytime during the past year?	Yes	13 (8.7%)	2 (3.4%)	1 (2.6%)
	No	136 (91.3%)	56 (96.6%)	38 (97.4%)
	Total Valid Response	149 (100.0%)	58 (100.0%)	39 (100.0%)
	Total missing	39	4	1

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

# EXP 5.2: Age group 18-39 years

 $NB~\cite{Bellin} 12]:~DED=respondents~with~DED="Yes"~minus~respondents~with~DME="Yes".$ 

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

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



Item	Response	Without DED (%)	With DED (%)	With DME (%)
Are you currently working?	Working for pay	30 (65.2%)	5 (50.0%)	3 (75.0%)
	Working without pay at home (e.g. housework, farming)	2 (4.3%)	0 (0.0%)	0 (0.0%)
	Volunteering	1 (2.2%)	0 (0.0%)	0 (0.0%)
	Retired	0 (0.0%)	1 (10.0%)	1 (25.0%)
	Student	9 (19.6%)	0 (0.0%)	0 (0.0%)
	Not working	4 (8.7%)	4 (40.0%)	0 (0.0%)
	Total Valid Response	46 (100.0%)	10 (100.0%)	4 (100.0%)
	Total missing	9	0	0
Do you receive assistance from the government?	Income assistance	1 (2.4%)	1 (10.0%)	0 (0.0%)
	Medical assistance	2 (4.9%)	0 (0.0%)	0 (0.0%)
	Food assistance	1 (2.4%)	0 (0.0%)	0 (0.0%)
	Housing assistance	2 (4.9%)	1 (10.0%)	0 (0.0%)
	None of the above	37 (90.2%)	8 (80.0%)	3 (100.0%)
	Total valid response	41 (100.0%)	10 (100.0%)	3 (100.0%)
	Total missing	14	0	1
Did you have trouble paying for food at anytime during the past year?	Yes	5 (10.9%)	0 (0.0%)	0 (0.0%)
	No	41 (89.1%)	10 (100.0%)	4 (100.0%)
	Total Valid Response	46 (100.0%)	10 (100.0%)	4 (100.0%)
	Total missing	9	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	38 (71.7%)	12 (44.4%)	8 (72.7%)

Item	Response	Without DED (%)	With DED (%)	With DME (%)
	Working without pay at home (e.g. housework, farming)	1 (1.9%)	0 (0.0%)	0 (0.0%)
	Volunteering	0 (0.0%)	5 (18.5%)	0 (0.0%)
	Retired	9 (17.0%)	8 (29.6%)	3 (27.3%)
	Student	1 (1.9%)	0 (0.0%)	0 (0.0%)
	Not working	4 (7.5%)	2 (7.4%)	0 (0.0%)
	Total Valid Response	53 (100.0%)	27 (100.0%)	11 (100.0%)
	Total missing	12	1	0
Do you receive assistance from the government?	Income assistance	2 (3.9%)	4 (16.0%)	1 (10.0%)
	Medical assistance	1 (2.0%)	0 (0.0%)	0 (0.0%)
	Food assistance	1 (2.0%)	0 (0.0%)	0 (0.0%)
	Housing assistance	1 (2.0%)	2 (8.0%)	0 (0.0%)
	Pension assistance	1 (2.0%)	1 (4.0%)	1 (10.0%)
	None of the above	45 (88.2%)	19 (76.0%)	8 (80.0%)
	Total valid response	51 (100.0%)	25 (100.0%)	10 (100.0%)
	Total missing	14	3	1
Did you have trouble paying for food at anytime during the past year?	Yes	5 (9.3%)	2 (8.0%)	1 (10.0%)
	No	49 (90.7%)	23 (92.0%)	9 (90.0%)
	Total Valid Response	54 (100.0%)	25 (100.0%)	10 (100.0%)
	Total missing	11	3	1

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

# EXP 5.4: Age group 60-79 years

Item	Response	Without DED (%)	With DED (%)	With DME (%)
Are you currently working?	Working for pay	13 (27.7%)	2 (9.1%)	1 (4.8%)
	Working without pay at home (e.g. housework,	1 (2.1%)	0 (0.0%)	1 (4.8%)



Item	Response	Without DED (%)	With DED (%)	With DME (%)
	farming)			
	Volunteering	1 (2.1%)	0 (0.0%)	0 (0.0%)
	Retired	29 (61.7%)	20 (90.9%)	19 (90.5%)
	Not working	3 (6.4%)	0 (0.0%)	0 (0.0%)
	Total Valid Response	47 (100.0%)	22 (100.0%)	21 (100.0%)
	Total missing	16	1	0
Do you receive assistance from the government?	Income assistance	1 (2.2%)	1 (4.5%)	1 (5.3%)
	Medical assistance	0 (0.0%)	0 (0.0%)	3 (15.8%)
	Housing assistance	0 (0.0%)	1 (4.5%)	0 (0.0%)
	Pension assistance	3 (6.5%)	2 (9.1%)	3 (15.8%)
	None of the above	42 (91.3%)	20 (90.9%)	12 (63.2%)
	Total valid response	46 (100.0%)	22 (100.0%)	19 (100.0%)
	Total missing	17	1	2
Did you have trouble paying for food at anytime during the past year?	Yes	3 (6.4%)	0 (0.0%)	0 (0.0%)
	No	44 (93.6%)	22 (100.0%)	21 (100.0%)
	Total Valid Response	47 (100.0%)	22 (100.0%)	21 (100.0%)
	Total missing	16	1	0

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

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

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

# EXP 5.5: Age group 80+ years

Item	Response	Without DED (%)	With DED (%)	With DME (%)
Are you currently working?	Retired	2 (100.0%)	0 (0.0%)	3 (75.0%)
	Not working	0 (0.0%)	1 (100.0%)	1 (25.0%)
	Total Valid Response	2 (100.0%)	1 (100.0%)	4 (100.0%)
	Total missing	3	0	0

Item	Response	Without DED (%)	With DED (%)	With DME (%)
Do you receive assistance from the government?	None of the above	2 (100.0%)	1 (100.0%)	4 (100.0%)
	Total valid response	2 (100.0%)	1 (100.0%)	4 (100.0%)
	Total missing	3	0	0
Did you have trouble paying for food at anytime during the past year?	No	2 (100.0%)	1 (100.0%)	4 (100.0%)
	Total Valid Response	2 (100.0%)	1 (100.0%)	4 (100.0%)
	Total missing	3	0	0

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

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

Group	Subgroup	All respondents	Type 1 diabetes	Type 2 diabetes	With DED (%)	With DME (%)
All respondents		290 (100%)	172 (59.3%)	113 (39.0%)	62 (21.4%)	40 (13.8%)
Gender	Male	121 (48.6%)	60 (49.6%)	60 (49.6%)	32 (26.4%)	22 (18.2%)
	Female	128 (51.4%)	93 (72.7%)	33 (25.8%)	29 (22.7%)	18 (14.1%)
	Total Missing	41	19	20	1	0
Age	18-39 yrs	69 (23.8%)	56 (81.2%)	12 (17.4%)	10 (14.5%)	4 (5.8%)
	40-59 yrs	104 (35.9%)	71 (68.3%)	32 (30.8%)	28 (26.9%)	11 (10.6%)
	60-79 yrs	107 (36.9%)	45 (42.1%)	60 (56.1%)	23 (21.5%)	21 (19.6%)
	80 yrs and over	10 (3.4%)	0 (0.0%)	9 (90.0%)	1 (10.0%)	4 (40.0%)
Time since diagnosis	Within the last year	13 (4.6%)	1 (7.7%)	11 (84.6%)	1 (7.7%)	0 (0.0%)
	1 - 5 years ago	44 (15.4%)	16 (36.4%)	26 (59.1%)	2 (4.5%)	3 (6.8%)
	6 - 10 years ago	32 (11.2%)	11 (34.4%)	21 (65.6%)	1 (3.1%)	2 (6.3%)
	11 - 15 years ago	37 (13.0%)	17 (45.9%)	19 (51.4%)	3 (8.1%)	3 (8.1%)

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



Group	Subgroup	All respondents	Type 1 diabetes	Type 2 diabetes	With DED (%)	With DME (%)
	16 - 20 years ago	23 (8.1%)	13 (56.5%)	10 (43.5%)	4 (17.4%)	2 (8.7%)
	21 years ago or longer	132 (46.3%)	110 (83.3%)	22 (16.7%)	51 (38.6%)	30 (22.7%)
	Don't know/Not sure	4 (1.4%)	1 (25.0%)	2 (50.0%)	0 (0.0%)	0 (0.0%)
	Total Missing	5	3	2	0	0
Control of Diabetes	Controlled	220 (83.0%)	134 (60.9%)	84 (38.2%)	44 (20.0%)	34 (15.5%)
	Not controlled	38 (14.3%)	24 (63.2%)	13 (34.2%)	16 (42.1%)	4 (10.5%)
	Don't know/Not sure	7 (2.6%)	2 (28.6%)	4 (57.1%)	1 (14.3%)	2 (28.6%)
	Total Missing	25	12	12	1	0

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

Question	Response	With DED n (%)	With DME n (%)
Have you had any treatment for diabetic eye disease?	Yes	45 (72.6%)	32 (86.5%)
	No	16 (25.8%)	4 (10.8%)
	Don't know/Not sure	1 (1.6%)	1 (2.7%)
	Total valid response	62 (100.0%)	37 (100.0%)
	Total missing	0	3
What treatment did you receive?	Laser	38 (84.4%)	29 (90.6%)
	Anti-VEGF	7 (15.6%)	17 (53.1%)
	Surgery	19 (42.2%)	12 (37.5%)
	Other	9 (20.0%)	1 (3.1%)
	Total valid response	45 (100.0%)	32 (100.0%)
	Total missing	17	8
Did you complete the treatment?	Yes	33 (73.3%)	15 (46.9%)

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

 $<sup>{\</sup>it NB~[3]: Percentages~within~groups~are~calculated~from~non-missing~data~for~that~question.}$ 

Question	Response	With DED n (%)	With DME n (%)
	No	1 (2.2%)	2 (6.3%)
	Still receiving treatment	10 (22.2%)	15 (46.9%)
	Don't know/Not sure	1 (2.2%)	0 (0.0%)
	Total valid response	45 (100.0%)	32 (100.0%)
	Total missing	17	8
Do you feel that the treatment worked?	Yes, and vision improved	6 (13.6%)	7 (23.3%)
	Yes, but vision stayed the same	21 (47.7%)	11 (36.7%)
	No	17 (38.6%)	7 (23.3%)
	Still waiting to know	0 (0.0%)	3 (10.0%)
	Don't know/Not sure	0 (0.0%)	2 (6.7%)
	Total valid response	44 (100.0%)	30 (100.0%)
	Total missing	18	10
What is/are the reason(s) that you did not complete the treatment?	Treatment was not effective	0 (0.0%)	2 (100.0%)
	Other	1 (100.0%)	0 (0.0%)
	Total valid response	1 (100.0%)	2 (100.0%)
	Total missing	61	38
What are the reason(s) that you have not had treatment for diabetic eye disease?	My doctor did not recommend any treatment	11 (68.8%)	1 (25.0%)
	Treatment would not be effective	2 (12.5%)	1 (25.0%)
	Treatment is not accessible	0 (0.0%)	1 (25.0%)
	Still waiting for treatment	2 (12.5%)	1 (25.0%)
	Too expensive	1 (6.3%)	0 (0.0%)
	I'm fearful of treatment	1 (6.3%)	0 (0.0%)
	Other	2 (12.5%)	0 (0.0%)
	Total valid response	16 (100.0%)	4 (100.0%)
	Total missing	46	36

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.













