

The Diabetic Retinopathy Barometer Report

Global Findings



Photo: Fernanda Pinheiro de Souza



At an unprecedented time in history with a rapidly ageing global population and a burgeoning diabetes epidemic the Diabetic Retinopathy (DR) Barometer Study represents a body of work supported by thousands of adults with diabetes, health care professionals from many disciplines and hundreds of organisations and agencies working in the field of ageing, diabetes and eye health.

Title: The Diabetic Retinopathy Barometer Report Global Findings

Format: Electronic book

This publication has been assigned: 978-0-9688407-2-6

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Acknowledgements

The IFA, IDF and IAPB would like to acknowledge and thank the many organizations and health care professionals from 41 countries that assisted in the dissemination of patient and provider surveys.

We especially recognize Dr William Li and the Angiogenesis Foundation for their specific advice, collaboration and contribution. All of these contributions and support were pivotal to the success of the DR Barometer Study.

This research was made possible with support from Bayer Pharma AG.



“Addressing barriers to eye screening is a critical policy issue that was examined through the views of patients and health care professionals”

Executive Summary

This unique multi-sectoral approach across 41 countries was only possible because all believed in the importance of the central premise, that is, diabetic retinopathy (DR) and diabetic macular edema (DME) are preventable diseases. Prevention is however only possible if those millions of people with diabetes around the world are informed and act on this information to have the necessary eye exams followed by appropriate and necessary treatments delivered by qualified professionals.

In essence, it is critical that integrated care is patient-centric with a clear focus on the best possible functional outcomes for the patient and indirectly their family and society.

The study sought in broad terms, to assess the awareness of diabetic eye disease (DED), access, and barriers to diabetes management, including screening and timely treatment. The views of nearly 7,000 adults with diabetes and health care professionals were gathered in this multi-method study, which not only highlighted good practice, but also emphasised the urgent need to address gaps in the healthcare system.

Health care professionals were viewed as the most trusted source of information about diabetes, yet health organisations, the health educator, the pharmacist, and family also play important roles with respect to education. A trend globally, reflected in most countries was the increasing use of the internet about diabetes and associated complications.

Many of those surveyed struggled with the management of their diabetic condition with some issues within their personal control such as eating the right foods and balancing the responsibilities of family and work without compromising health. A series of environmental and systemic barriers such as the high cost of services, long wait times to schedule an appointment and long wait times on the day of the appointment also impacted the ability of adults with diabetes to gain the accurate and timely advice and care they need.

Even though many respondents expressed anxiety in dealing with their condition very few were enrolled in a diabetes management programme. Yet this may be because programmes were either not available in their country or people were not aware of them.

Free or low cost medicines were essential to being able to cope well with diabetes, as was support from family or friends, health education and information, and professional coordination of health care services amongst providers.

There was a relatively high awareness of the complications associated with diabetes, and vision loss was by far the most concerning in many countries, followed by cardiovascular and kidney disease. Despite the concern about complications, and specifically vision loss, a certain proportion of respondents did not want to think about their condition, or do anything about preventing further deterioration.

Those with DME and DR were more likely to experience life-changing complications with more than one in three having neuropathy, which was two times more than those without DED. Across all complications, there was often a percentage increase for those with DED and DME versus those without DED. This was not the case in all countries especially where sample sizes were notably very small.

Executive Summary

Generally, health professionals shared information with colleagues to optimise patient care management however, the degree to which this initiative improved care was undetermined.

Addressing barriers to eye screening is a critical policy issue that was examined through the views of patients and health care professionals. While most respondents had received an eye exam, which is understandable considering the purposeful sample, there remained many barriers including the high costs of exams, a fear of the treatment or the results, and long wait times either to schedule an appointment or on the day of the appointment. Reminders to patients to schedule an appointment were not a routine process for practices.

Evidence shows that the relationship between the patient and the health care professional is vital to ensure realistic and optimal patient outcomes. An important, yet unexpected, finding from the study was that in some countries more than a quarter of adults with diabetes had either never had a conversation about eye complications with their doctor or it only took place when symptoms were present. Equally concerning were the myths and perceptions around vision changes with a significant proportion of people thinking that vision problems (in the context of diabetes) were a normal part of ageing and some choosing not to make any special effort to prevent vision problems.

A lack of understanding about the importance and urgency of timely screening and treatment could in part explain the finding from health care professionals that patients present when vision loss had already occurred and sometimes too late for treatment. However, other barriers related to the health system are contributing factors such as limited access to patient education on DR and DME, the referral

process being complicated, and at times inadequate, some clinics were too small or ill equipped for the complex treatment regimens, and the cost of care was prohibitive.

Reimbursement restrictions on approved therapies and the lack of universal access to the most appropriate treatments results in a system which is unequal, a finding also expressed by patients who felt their income and where they lived impacted their ability to access care. In addition, most patients described almost insurmountable barriers such as travelling to appointments because of distance from the clinic, and the inability to drive or use public transport. Despite these barriers, most respondents preferred a proactive approach to prevent further vision loss rather than waiting until there were undeniable and potentially irreversible changes.

Patient and professional education is very much at the heart of a proactive approach in the management of diabetes. Significantly, there was a serious gap in information on diabetes and potential eye complications from health care professionals. Over half of the health care professionals either did not have any information on diabetes and potential eye complications or the information on eye complications was insufficient. Furthermore, one in five ophthalmologists said that the lack of universal guidelines on referrals and screening was a significant challenge for improving patient outcomes in DED. Some providers either did not have access to protocols or the protocols available were not used.

While most ophthalmologists had speciality training in the diagnosis or treatment of DR and / or clinically significant DME there was a small percentage who did not have this training. Overall, there was interest in further education and certification on DME, angiogenesis and anti-VEGF therapies.

Ophthalmologists acknowledged the complex, and sometimes inadequate, patient referral pathways, a lack of integrated care, and ineffective screening services as serious systemic challenges that contribute to poor overall outcomes in diabetic eye health. Aside from the system issues, specialists in the treatment of DR and DME are strongly influenced by the duration of diabetes, high glucose levels, and the presence of co-morbidities.

Treatment modalities, in relation to respondents with DED and DME, were most commonly laser, followed by surgery, and anti-VEGF therapy. Whether treatment had been completed or was continuing, most respondents felt that it had been successful and either their vision had improved or their vision had at least stayed the same. The main reason for not undergoing treatment was that the attending doctor or specialist did not make the recommendation, although for others the cost of treatment was prohibitive.

The social and economic burden of having a diagnosis of DR and DME was “unambiguously tough” and touched the lives of not only the person with diabetes but also their family, friends and work colleagues. While it is difficult to quantify “burden” in terms of dollar and cents, the study findings left no doubt as to the impact that DR and DME had on a person’s function, their ability to be autonomous and independent, to be in paid work, and to be engaged in normal family life and social activities. One in three had difficulties driving a car, a quarter had trouble working or keeping a job, and undertaking basic household responsibilities, such as cooking or cleaning. In addition, leisure activities and travelling generally were commonly seen as problematic.

Limitations in daily activities, including the basic management of their underlying condition, were far more prevalent for those with DED and DME than those without DED. For one in five of these respondents poor diabetes management, combined with difficulties in exercising and cooking is a set of factors that could lead to further complications. It was not surprising therefore that those with DED and DME were more likely to rate their health as fair or poor and have physically unhealthy days and restricted daily activities.

With diminished functional ability and difficulty in working and travelling, the impact of having DED and DME goes from the individual to the state with a greater likelihood of needing government assistance and in particular income and food assistance.

The global healthcare burden, coupled with the extraordinary personal and societal costs related to DED and DME profiled in this study, should be of concern not only to governmental decision makers but also to all those with diabetes and their families. The study showed clearly that those with diabetes and associated vision loss experienced a significantly diminished sense of well-being, as well as a loss of autonomy and, for some, changes to their role and responsibilities within the family.

Global demographic shifts in the decades to come are likely to be associated with a massive increase in the rates of diabetes. Considering the findings of the DR Barometer Study “now” is the time to act to develop cost-effective strategies to prevent diabetes-related vision loss.



79%

79% of respondents said their vision impairment due to **DR or DME** made **everyday activities difficult**, such as driving, working and cooking or cleaning their home, and in some cases impossible



Introduction

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).

In the context of this study, DED comprises diabetic retinopathy (DR) and diabetic macular edema (DME).

To address the complexities of optimizing eye health in people living with diabetes around the globe, the Diabetic Retinopathy (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.

The DR Barometer Study, conducted in 41 countries, elicited unique insights into the real-life experiences of people living with DED and health care professionals across the care pathway and patient journey.

Vision loss is preventable if DED is identified in its early stages, as effective treatments are now available to prevent progression.⁽¹⁾ Despite the serious risks, little has been published regarding the global and country-specific awareness, prevention and effective management of diabetes-related vision impairment.

These findings, presented in the global and country reports, are vital to inform improved clinical management of diabetes and screening for DED as well as the development and implementation of national health policies to address the barriers identified in the study.

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 overall health, functional ability, and well-being, ensuring that each, and every, person diagnosed with diabetes has the capacity and capabilities to contribute both to their family and the wider community.

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

Contents

Executive Summary	1
Introduction	5
Background	11
Diabetes	11
Diabetic Retinopathy and Diabetic Macular Edema	12
The Current Outlook for DR	13
Diabetic Retinopathy Barometer Study	14
Methodology	17
Literature Review	17
Phase I: Qualitative Study	18
Limitations of the Phase I Study	18
Phase II: Quantitative Study	19
Data Preparation	19
General Considerations	20
Accounting for Respondents	20
Analysis Corresponding to the Study Objectives	20
Adults with Diabetes Survey	20
Health Care Professionals Survey	20
Additional Exploratory Analysis	21
Limitations of the Phase II Study	21
DR Phase I: Qualitative Report	23
Key Demographic Characteristics	23
Adults with Diabetes	3
Health Care Professionals	23
Impact of diabetic retinopathy and vision impairment	24
Diabetes Management	26
Engagement in Care: Predictors and Practice	26
Diabetes Diagnosis	26
Knowledge and Awareness	26
Information Sources	28
Vision Screening	28
Provider Referrals	29
Treatment of Diabetic Eye Disease and Diabetic Macular Edema	32
Coordinating Care	34
Supportive Services	35
Systemic Barriers and Facilitators to Care	37
Availability of services	37
Wait Times	38
Cost and Payment	39
Travel	40
Discussion	42
Barriers to Screening: Inadequate Awareness, Motivation, and Direction	42
Barriers to Treatment and Care	43
Limitations of the study	43

DR Phase II: Quantitative Results	47
Key Demographic Characteristics	47
Adults with Diabetes	47
Health Care Professionals	54
Knowledge and Management of Diabetes	54
Adults with Diabetes	54
Health Care Professionals	58
Nature and Information about Complications	59
Screening for Diabetic Eye Disease	61
Adults with Diabetes	61
Health Care Professionals	62
Diabetic Eye Disease and Diabetic Macular Edema	64
Potential Factors Contributing to the Onset of Diabetic Eye Disease	67
Treatment of Diabetic Eye Disease and Diabetic Macular Edema	69
Impact of Diabetic Eye Disease and Diabetic Macular Edema	71
Impact on Employment Status	72
Reliance on Government Assistance	75
Barriers in the Care Pathway	79
.....	
Summary	83
Study Populations	84
Awareness and Information for the Management of	85
Diabetes and Diabetes-related Eye Complications	
Guidelines and Protocols for the Detection and	87
Management of Diabetes-Related Eye Disease	
Gaps and Barriers to Eye Care and Referral	87
Screening and Diagnosis	88
Diagnosis and Treatment of DED and DME	89
Burden and Impact of DED and DME	90
.....	
Recommendations	93
Research and Policy Agenda Setting	93
Awareness and Information for the management of diabetes	94
and diabetes-related eye complications	
Guidelines and Protocols	94
Screening and Diagnosis addressing Gaps and Barriers to Eye Care and Referral	95
Treatment of DED and DME and Rehabilitation	95
.....	
Conclusion	97
.....	
References	98
.....	

The DR Barometer Global Report: Overview

The DR Barometer study was conducted in 41 countries. Globally 4,340 adults with diabetes and 2,329 health care professionals provided new information about the experiences of living with, managing and treating diabetes, DR and DME.

38%

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



44%

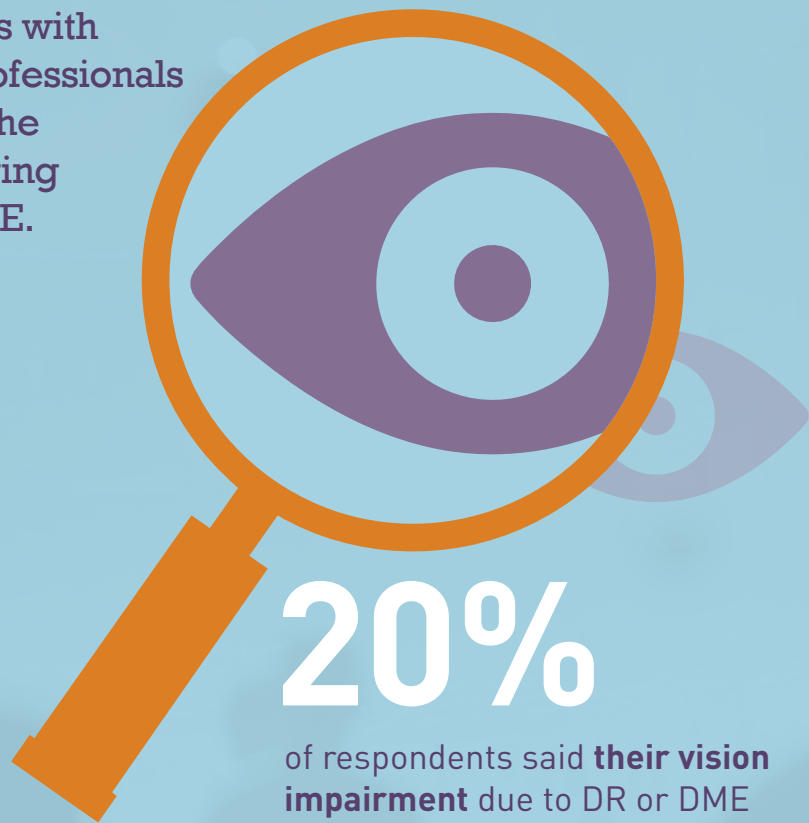
of all providers **did not have, or did not use, written protocols** for the management of diabetes-related vision loss



DED: Diabetic Eye Disease

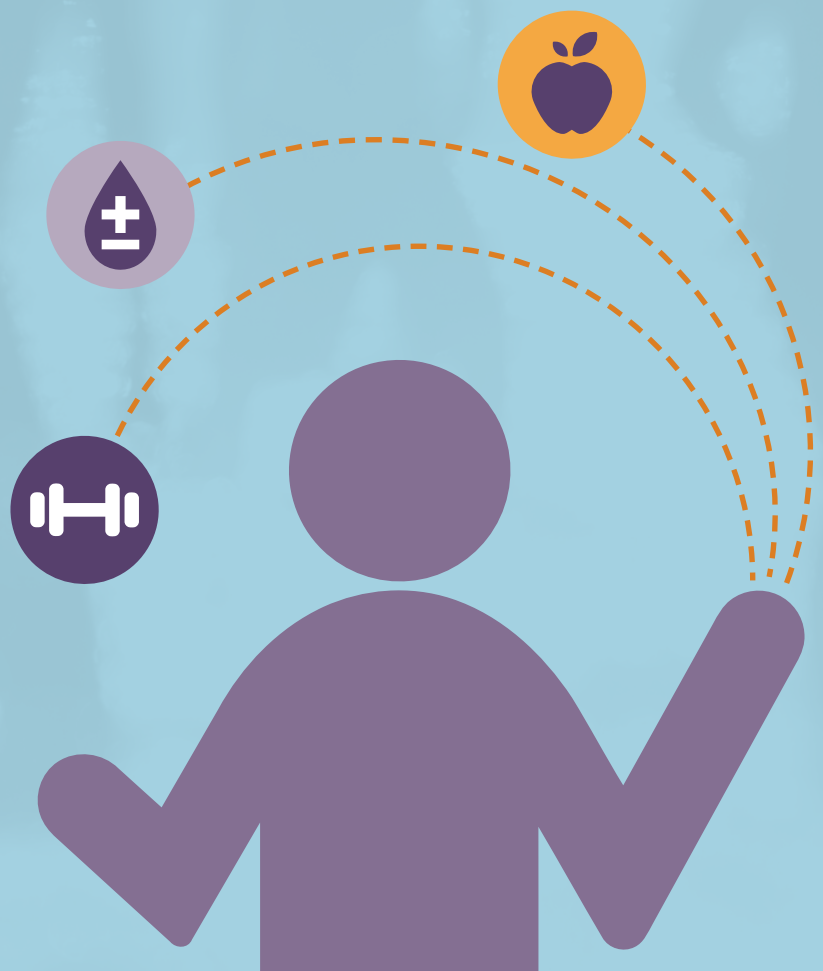
DR: Diabetic Retinopathy

DME: Diabetic Macular Edema



20%

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





79%

79% of respondents said their vision impairment due to **DR or DME made everyday activities difficult**, such as driving, working and cooking or cleaning their home, and in some cases impossible



69%

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



27%

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



21%

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





21%

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



Background

Diabetes poses one of the greatest challenges to current health care systems worldwide. According to the IDF, an estimated 415 million adults globally were living with diabetes in 2015, with this figure set to rise to 642 million by 2040¹, constituting some 10% of the global adult population aged between 20 and 79.

Diabetes

The World Health Organization (WHO) estimates indicate that high blood glucose in people with diabetes, is now the third highest risk factor for premature mortality after high blood pressure and smoking,² accounting for 5 million adult deaths around the world in 2015.¹

This exceeds the 3.6 million deaths estimated to be due to HIV/AIDS, tuberculosis, and malaria combined.³ However, despite the rising worldwide prevalence of diabetes, many governments and health professionals are still unaware of the full social and economic impact of the condition and its many associated complications, particularly with respect to ageing populations. This lack of information and insight creates a barrier to implementing effective prevention strategies and treatment for diabetes and its complications.

There are two main types of diabetes. Type 1 diabetes is a chronic autoimmune disease in which the immune system destroys the insulin producing cells in the pancreas. People with type 1 diabetes need daily treatment with insulin to control their levels of blood glucose. Type 1 diabetes is much less common than type 2 diabetes, although it is increasing at about 3% each year globally.

⁽¹⁾ The onset of type 1 diabetes is usually in childhood or adolescence, but it can affect people of any age.

Type 2 diabetes is much more common and is characterized by insulin resistance and/or the body producing insufficient insulin. Rapid urbanization associated with unhealthy diets and reduced physical activity, and an ageing population, has been associated in many countries with large increases in the incidence of type 2 diabetes⁴. Type 2 diabetes can often be controlled by adopting a healthy diet and increased physical activity but may also require medication, including insulin or oral medicines. Until recently, type 2 diabetes was seen mainly in mid-life to older age groups, however, it is now increasingly seen in children and adolescents.¹⁷

In high-income countries, it is estimated that around 87-91% of people with diabetes have type 2 diabetes, with a further 7-12% with type 1 diabetes and 1-3% with rarer forms such as monogenic diabetes.^{5, 6, 7, 8} It is difficult to estimate figures for the relative proportions of type 1 to type 2 diabetes in low and middle-income countries as to date insufficient data has been collected.

Although approximately 8.8% of the global adult population has diabetes, about half remain undiagnosed as there are often few symptoms present in the early stages of type 2 diabetes. Moreover, symptoms may occur, but not be recognized as being related to diabetes.⁹ Delayed diagnosis is a substantial problem as it increases the risk of developing complications, due to the damage caused by prolonged elevation of glucose concentrations circulating in the blood (hyperglycemia).¹⁸

Background

Diabetic Retinopathy and Diabetic Macular Edema

In the context of this study, DED comprises diabetic retinopathy (DR) and diabetic macular edema (DME).

Diabetic retinopathy (DR) affects the small blood vessels of the retina of the eye in people with diabetes. The vessels swell and leak liquid into the retina, blurring the vision and sometimes leading to blindness.¹⁹ Persistent hyperglycemia can damage small blood vessels (microvasculature) in organs such as the eye, leading to DR.¹ It is estimated that approximately 93 million people worldwide have DR¹⁰, and that a third of the global diabetic population are expected to develop some form of retinopathy in their lifetime.¹⁹



93m

It is estimated that approximately **93 million people worldwide** have DR

DR is a common complication of diabetes and can result in severe visual impairment. It is currently a leading cause of vision loss of people with diabetes in many countries^{11, 12}. The condition is characterized by damage to the small blood vessels supplying the retina, resulting in the leakage or blockage of the retinal capillaries. Often displaying no early warning signs, DR is a serious clinical consequence of diabetes and if left untreated can lead to blindness.¹

Trained health professionals grade DR according to its severity, ranging from mild non-proliferative DR (NPDR) to proliferative

DR (PDR). In early stage retinopathy (NPDR), microvascular damage appears in the retina. If retinopathy remains untreated, it can progress further to a proliferative form (PDR) where impaired blood flow to the retina leads to proliferation of new blood vessels that grow from the retina into the vitreous cavity. These new vessels are extremely fragile and can cause significant vitreous hemorrhage leading to scarring of the retina and tractional retinal detachment, all of which can significantly lead to impaired vision or blindness.¹⁹

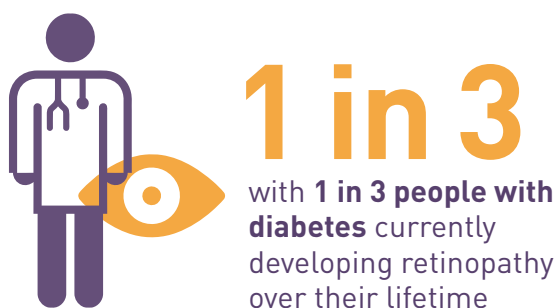
Diabetic macular edema (DME) is a further complication of retinopathy, which can occur at any stage. It is characterized by a thickening of the macular region of the retina due to an accumulation of fluid from leaking blood vessels. It is associated with significant vision loss, as the macula is the part of the retina that is used for sharp focus and central vision.¹⁹

As DED is largely asymptomatic in the early stages, it is essential that people with diabetes have retinal screening on a regular basis in order to detect DR and DME.

⁽¹⁾ A number of methods are available for diagnosis of DR, including ophthalmoscopy, optical coherence tomography, retinal photography and fluorescein angiography. Once sight-threatening DR is detected, there are then a number of effective treatments available such as laser treatment (photocoagulation), intravitreal anti-VEGF drugs, intravitreal steroid injections, and vitrectomy. Unfortunately, in many low and middle-income countries, there is a lack of availability of screening and treatment for DR.

Many of these treatments can prevent vision loss, stabilize vision and in some cases improve vision if performed early.²⁰ Therefore, it is essential that people

with diabetes are educated about the importance of regular retinal screening, and given efficient and timely access to these services. Moreover, motivating individuals to implement personal management strategies such as healthy lifestyle choices regarding nutrition and exercise, and encouraging them to work with their health professionals towards proper blood glucose and blood pressure control, also plays an important role in reducing the risk of the development or progression of DR.¹⁹



The Current Outlook for DR

As the global population ages and with rapidly increasing rates of obesity and diabetes, cases of retinopathy are set to rise. Projections suggest that DR will become the world's leading cause of blindness over the next three decades¹³, with 1 in 3 people with diabetes currently developing retinopathy over their lifetime.¹⁴ Whilst diabetes and DR are a considerable global problem, it is estimated that 75% of people with diabetes live in low and middle-income countries⁽¹⁾ where health care facilities for managing diabetes are poor and public awareness is low. Thus, many people with diabetes will have suboptimal control, with significantly increased risk of developing DR and vision loss.¹⁹ DED has serious implications both on a personal and social level, as the burden of visual impairment and blindness incurs a loss of earning capacity as well as a potential need for social and care support.²¹

To combat the inevitable rise in DR, good quality epidemiological data on its global burden is vital to inform the planning and implementation of improved public health policies and programmes. Currently, whilst much has been published on the prevalence of diabetes^{15, 16} surprisingly less data are available on diabetic complications such as DR and DME, particularly in low and middle-income countries. Indeed, epidemiological studies of DR have not been comprehensive in their coverage of the global populace and have been inconsistent in their methods, making it difficult to compare DR prevalence around the world.

Further barriers facing people at risk of DR and DME include a lack of awareness of the risks of developing DED, as well as limited access to screening and treatment according to recommended health care guidelines.²² The full impact and extent of these problems is not clear as there is limited data collected from patients and their providers. With more targeted information, further insights can be obtained on the factors that impact health care delivery, which is essential to understanding how services can be improved to reduce the risk of vision loss for people with diabetes.



Photo: Gitika Saksena

Background

Diabetic Retinopathy Barometer Study

To investigate the global, regional, and specific country issues surrounding DED, including DR and DME, the International Federation on Ageing (IFA), the International Agency for the Prevention of Blindness (IAPB) and the International Diabetes Federation (IDF) conducted a comprehensive, two-phase, multi-country study of the condition.

Phase I involved interviews in eight countries that represented a cross section of regions and income levels. In each country, interviews were administered with nine people diagnosed with diabetes, six health care professionals, and 1-3 key informants with knowledge about relevant policies and practice. These semi-structured interviews provided information on the experiences of adults with diabetes, including those that have DR and / or DME, and the perspective of the health care professionals.

Phase II was based on both desk research and the generation of new data in the form of a specifically designed, web-based survey of adults with diabetes and health care professionals in 41 countries. The desk research involved a review of the current literature on retinopathy to gain both a global and regional perspective on its prevalence, incidence, and risk factors. Access to care, examining service use and reported practice guidelines for prevention, screening, and management were examined together with the data on the social and economic burden.

This survey investigated the gaps in knowledge and clinical practice for DED amongst health professionals and adults with diabetes across the six regions of the WHO. These data, capturing the current landscape for the diagnosis, treatment, and management of DED in low, middle, and high-income countries, were derived from detailed patient and provider surveys. The countries studied were defined according to the WHO regional structure, namely, the African region, the Eastern Mediterranean region, the European region, the Region of the Americas, the South-East Asian region, and the Western Pacific region.

The primary purpose of the study was to ascertain levels of awareness amongst adults with diabetes and health care professionals (such as primary health professionals, diabetes specialists and ophthalmologists) of the prevention, diagnosis, and treatment of DED, comprising DR and DME, and to assess the clinical management, availability, and use of patient support services for these conditions.



The specific objectives of the study included:

1. Assess the availability and use of programs and services that support individuals with diabetes
2. Assess the level of awareness of prevention, prognosis, and treatment of DED among adults with diabetes, and health care professionals
3. Identify factors that impact the prevention and clinical management of DED
4. Assess the social and economic consequences of DED and vision impairment
5. Provide evidence for the United Nations (UN) and World Health Organization (WHO) targets relevant to older persons, vision, and diabetes, and the integration of new information in national health policies

This report presents the key findings of Phase I and Phase II of the DR Barometer study. It is intended that this report will be used to increase awareness of issues associated with DED among both health professionals and people with diabetes, as well as to inform policy and practice related to DED and vision loss across countries.

New country-specific information from this study will help to highlight the impact of DR worldwide, and aims to prompt greater dialogue about the potential strategies to address and manage this mounting global challenge.



Photo: Astadi Priyanto

The study population of adults with diabetes participating in the patient survey was self-selected from patient organisations as well as membership organisations of older adults (seniors) and as such is more likely to be engaged and motivated in the management of their diabetes. Likewise, the provider respondents were self-selected and the same considerations should be applied when interpreting the results.

Whilst 4,340 adults with diabetes and 2,329 health care providers across 41 countries completed the comprehensive surveys, they may not be representative of the broader population of these constituents. This evidence does however provide a rich resource for generating unique insights into the real-life experiences of adults living with diabetes and those providers who are active in the prevention, screening, and treatment of DR.



38%
of patients said that
**long wait times for an
appointment** were a
barrier to eye exams

Methodology

The DR Barometer Study was designed to examine, among health professionals and adults with diabetes, the level of awareness of diabetic retinopathy (DR) and diabetic macular edema (DME), the availability and nature of health and support services for people with these conditions, and the associated social and economic disease burden.

The project included a global literature review, in-depth interviews of adults with diabetes and health care providers in specific countries, and a web-based survey of adults with diabetes and health care professionals across the six World Health Organization (WHO) regions.

This mixed approach incorporating both qualitative and quantitative methods was necessary given the broad range of topics, the varied experiences of the respondents as well as the complexity of country differences. This section of the report describes the data sources and the methods of analysis used in the literature review and the web-based survey.

Literature Review

The literature review was conducted using journal articles, reports and other relevant materials from scientific literature and international and national organisations and agencies, focused on epidemiology, awareness, disease burden and policy and practice. The purpose of the review was to provide a baseline understanding of the literature relating to the awareness, treatment and management of patients with DR and DME, and as such provided context for data collected in the qualitative and quantitative phases of the study.

A search of all publications in PubMed was limited to humans. Further criteria using the following key terms were applied to refine the approach: diabetes mellitus complication, macular edema, diabetic retinopathy, vision

disorders or eye disease, and screening, diagnosis, prevalence, guidelines, economics, therapies, self-care, disease management.

Other supplemental sources in the review included the IDF Atlas 2015¹ and Diabetes Eye Health: A guide for health professionals².

Quantitative and qualitative information on DR and DME relating to: incidence and prevalence, risk factors, reported practice guidelines for prevention, screening, and management, access to healthcare services, education and training, and relevant policies and national standards were obtained from scientific papers and supplemental sources.

This information was synthesised and presented at a global level and by region and country to enable the evaluation of the burden as well as to provide an understanding of differences that may exist between countries. Quantitative information, such as prevalence and incidence, was presented as population estimates along with measures of the uncertainty, when given. Qualitative information was summarised from the original source and used for additional context and evidence.

The extensive nature and depth of the literature review represents an important reference source for and beyond the DR Barometer Study. For this reason, partners decided to publish the Literature Review as a stand-alone document.

Methodology

Phase I: Qualitative Study

Phase I of the study used qualitative methods to examine the experience of providers (n=48) and adults with diabetes (n=73) across eight diverse countries. This component of the DR Barometer Study comprised 120 semi-structured interviews with a small sample of adults with diabetes (n = 9 per country, see Appendix I) and health care professionals (n = 6 per country, see Appendix II) in each of eight countries— Germany, Saudi Arabia, Japan, Romania, Mexico, Argentina, Uganda, and Bangladesh—which 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) (see Appendix III).

For adults with diabetes, topics included in the semi-structured interview were: background information (e.g., residence, education), health status, diabetes knowledge and management, knowledge and practices related to vision, and access and use of health and supportive services.

For health care professionals, topics included background information (e.g., specialty, practice settings, patient demographics), services provided to patients with diabetes, DR or DME, patient access to services, and perspectives on policy and practice relevant to DR at the national level.



Interviews were conducted in local languages and audio recorded, with translated transcriptions and reports for analysis. Interviewers also provided brief summaries of the findings and perceptions across interviews, as well as background information on the local health systems and healthcare access issues, so as to facilitate analysis of interview transcripts.

Data from the interviews were analysed for pre-identified themes consistent with the main study objectives, including awareness relevant to DR, availability and access to services, and practices at the local level.

Limitations of the Phase I Study

Phase I of the DR Barometer Study had certain limitations. First, although the sample size was relatively large for a qualitative study, given the diversity of respondents and socio-economic status of countries (eight countries, adults with diabetes as well as health care professionals) it is not possible to draw definitive conclusions. Furthermore, the need for a consistent research protocol across all countries precluded in-depth exploration of particular local level issues.

As the sample was often recruited through patient and civil society organisations as well as the practices of health care professionals the views may not represent the diversity of each population. Indeed, the participants may be more engaged than the general population.

Finally, although in-country interviewers were selected based on relevant experience and all interviewers received training on the research protocol, the results were variable, with some interviewers more successful at engaging participants in a rich and nuanced conversation, as compared to others.

Phase II: Quantitative Study

Phase II of the DR Barometer Study comprised two questionnaires, adults with diabetes (the patient survey) and health care professionals (the provider survey), conducted across 41 countries within the six regions of the WHO.

The patient survey comprised 46 questions divided into four sections covering respondent information, knowledge and current care for diabetes, screening, and quality of life (see Appendix IV). The provider survey comprised 43 questions covering provider and practice characteristics, and specific information from ophthalmologists (see Appendix V).

Data Preparation

The survey data was evaluated and cleaned prior to analysis. Implausible values were removed from the data, such as those that were not within the expected range or list of options. For example, some questions requested a numeric response within the range 1-30; any number that did not take a value within this range was excluded. Duplicate records were also removed as well as those respondents whose country information was missing. After cleaning, the data from all questions were incorporated into the analyses, including those marked to be skipped if certain parent responses were selected.

Country information was used to group respondents into regional groups as per the WHO regions (<http://www.who.int/about/regions/en/>) and into the WBIGs (<https://datahelpdesk.worldbank.org/knowledgebase/articles/906519>) according to high-income, upper-middle and low and lower-middle economies.

For the purpose of understanding the impact of the progression of DED, respondents to the patients' survey were assigned to the following subgroups:

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

Methodology

General Considerations

All data were summarised globally and by region and country. In general, continuous data were summarised using mean, standard deviation, minimum, median and maximum and categorical data using frequency counts and percentages. These summaries were inspected for general patterns and trends and further exploratory analysis was performed as appropriate. All analyses were performed using SAS version 9.4.

Every question, for which there was a plausible response, was included in the analysis, even if the response was inconsistent with the responses to other questions. An assessment of these inconsistencies showed that the occurrence was rare and therefore did not impact the results. In general, when a response to a question was missing, it was treated as missing and excluded from summaries of that question. Therefore, the denominators for summaries were the number of non-missing responses to each question, and frequencies and percentages were calculated from the non-missing values. Some key statistics, such as the proportion of respondents with DR or DME, were also presented relative to the total number of respondents regardless of missing responses (see Appendix VI).

Summary statistics were presented for all the data (global analysis) and then by WHO regions, with countries summarised within each region. All statistics were presented in the form of structured tables. Key results were also presented using graphics, such as bar charts and histograms, in order to facilitate interpretation of the data. Exact 95% confidence intervals for binomial proportions

were calculated for the incidence of DED and DME which was presented on forest plots

Accounting for Respondents

For each of the patient and provider datasets the following summaries were created to account for all respondents participating in the survey. The number of respondents was summarised in a table and presented in a consort diagram. The reasons for exclusion of any respondents and key information around any excluded responses were described. Further summaries showing the number of respondents by region and country were presented. Subgroup analyses also included the respondents in total and by region and country.

Analysis Corresponding to the Study Objectives

All analyses related to the primary study objectives were pre-specified and described in a statistical analysis plan that was agreed prior to conducting the analyses. The analysis plan described the approach taken to examine and present the data collected in the patient and provider surveys.

Adults with Diabetes Survey

The results were tabulated for each question and answer. For key questions with a range of answers, a histogram or bar chart was produced to show the percentage of each response.

All analyses were repeated for global, by region and by country. Where there was no data available for any region or country this was noted in the table as missing responses. Selected analyses were also repeated by subgroups and by WBIGs.

Health Care Professionals Survey

The results from the provider survey were summarised by question as per the order of the survey, including each of the provider subgroups of primary care provider, diabetes specialist provider, ophthalmologists and all providers.



Photo: Terry Cooper

Additional Exploratory Analysis

Further exploratory analyses were performed following the review of the initial analysis. These analyses enabled insight into the findings and for subgroups in particular, and provided further context for interpretation of the data. Any exploratory analyses were marked in the statistical tables, along with a description of the analyses.

Limitations of the Phase II Study

The Phase II study had a number of limitations. Although the sample size was large and provided useful information at a global level, the number of respondents varied considerably by country so analysis performed at a global level was heavily weighted in favour of those countries with the greatest number of respondents. Furthermore, the number of respondents in some countries and subgroups were too small to draw any definitive conclusions, but were useful to show broader trends when used alongside other responses.

As with the Phase I study, participants were largely recruited through patient and civil society organisations and the practices of health care professionals, so were more likely to be more engaged in care than others with diabetes and DED. Consequently, their experiences may differ from others.

The consistency with which information was collected varied between respondents resulting in missing data and implausible responses to some questions. The variation in the consistency of the information collected may reflect different levels of understanding of the terminology and cultural differences in language used within the survey.

As the data was collected from 41 countries, across many different languages, it is reasonable to assume some variation in the translation and understanding of medical and health terms. Indeed, a small number of respondents reported that they had DME and not DED, suggesting a lack of understanding of the survey or of their condition. In addition, in the patient survey the term DED rather than DR was used, so it may be that patients use these terms interchangeably.

In most analyses, missing data were excluded with the underlying assumption that the observed data provided a reasonable representation of the study population and that the results would be consistent regardless of missing data. The reasons for missing data were unknown and therefore not clear as to whether bias was introduced into the analysis as a result. However, where bias does exist, the impact is likely to be greatest in analyses involving a small number of observations.

For some questions, respondents were able to select multiple answers. Whilst this provided broader insights from patients and providers, it also poses a challenge when interpreting the results as the total number of responses for some questions is greater than the total sample size.



27%

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



Phase I: Qualitative Study

Phase I of the DR Barometer Study used qualitative methods to examine the experience of adults with diabetes (n=73) and health care professional (n=48) across eight diverse countries in order to contribute to assessing the awareness of DED, and access and barriers to diabetes management, including screening for DED and timely treatment.

Uniquely, the voices and views of patients and providers give life and insights into the complex nature of the care pathway within diverse health systems and most importantly the real impact of vision impairment and loss in a person's life and livelihood.

Key Demographic Characteristics

Adults with Diabetes

Seventy-three adult with diabetes were interviewed. Thirty-three had DR without DME and sixteen had DR with DME (see Table 4.1). Fifty-two percent were females, and most participants were in two age groups, 40-59 years (48%), and 60-74 years (37%). Close to two-thirds (64%) lived in an urban setting and about one third (34%) reported to be living in poverty.^a

Health Care Professionals

Forty-eight providers were interviewed (see Table 4.1). Twenty-nine percent of respondents were primary care providers, 13% diabetes educators, 17% endocrinologists or diabetes specialists, 19% ophthalmologists, and 19% retinal specialists. The majority (75%) worked in urban settings.

Table 4.1:
Characteristics of Study Participants

Characteristic	Participants with Diabetes (n=73)	Providers (n=48)
Country		
Argentina	9 (12%)	6 (13%)
Bangladesh	8 (11%)	6 (13%)
Germany	9 (12%)	6 (13%)
Japan	9 (12%)	6 (13%)
Mexico	10 (14%)	6 (13%)
Romania	10 (14%)	6 (13%)
Saudi Arabia	9 (12%)	6 (13%)
Uganda	9 (12%)	6 (13%)
Health educator		
Female	38 (52%)	22 (46%)
Male	35 (48%)	26 (54%)
Health educator		
18-39	4 (5%)	7 (15%)
40-59	36 (49%)	34 (71%)
60-74	27 (37%)	7 (15%)
75+	6 (8%)	0 (0%)
Residence		
Rural	26 (36%)	10 (21%)
Urban	47 (64%)	38 (79%)
Economic Status		
Below poverty	25 (34%)	-
Above poverty	43 (59%)	-
Missing	5 (7%)	-
Health Conditions		
Diabetes only	24 (33%)	-
Diabetic retinopathy (no DME)	33 (45%)	-
Diabetic macular edema	16 (22%)	-
Speciality		
Primary care provider	-	14 (29%)
Diabetes educator	-	6 (13%)
Endocrinologist	-	8 (17%)
Ophthalmologist	-	9 (19%)
Retinal specialist	-	9 (19%)
None of the above	5 (1.8%)	

Phase I: Qualitative Study



Impact of diabetic retinopathy and vision impairment

A number of respondents reported that they were forced to retire prematurely, some as early as their 30s and 40s, because of the consequence of DR such as vision loss and the inability to either function in their jobs and/or commute to work. They described the resulting economic hardships, as well as an increased reliance on governmental programmes, where available, and family members



Individual with diabetes,
age 59, Germany

“I am unemployed... I trained as an electrician and worked about 10 years in this job.

[I stopped working at age 31] because of the progressing loss of vision, because of diabetes the loss of vision happened...we originally had [a pension for blind people] of 585€.

Then it went down to 409€, then they eliminated it for one year, and when they established it again it was at 265€. So drastically cut.”

Vision loss also impacted daily life, including the capacity to continue, or feel comfortable with routine activities such as cooking, cleaning, reading, writing, and socializing. A number of patients described the many difficulties they had adjusting to the limitations and to the increased dependence on family members and others.

“Sometimes...I am in a hall for a social occasion, and I get very shy because, I cannot really recognise a relative or friend’s face.”

Individual with diabetes, age 60, Saudi Arabia



Individual with diabetes,
age 68, Argentina

“With this new macular thing, things have gotten pretty difficult... I have 20 or 30 books that I bought recently, and I haven’t been able to read them. I was at the grocery store the other day and I couldn’t see the price tags! Or, another day in which I had to ask another person to read something for me. That type of dependency makes me very upset.”

One 58-year-old person from Mexico noted that their vision loss had a greater negative impact than their amputation, as it affected their mobility to a greater degree.

Although public transportation was the norm in most countries, several participants described the implications of limitations with respect to driving.



Individual with diabetic
retinopathy, age 64,
Saudi Arabia

“The most important issue to me is the driving. Now I always avoid very crowded streets and the high roads where the strong car lights can really affect my driving ability. If it is not necessary, I really don’t go out in the evening.”



Phase I: Qualitative Study

Diabetes Management

Vision impairment also impacted a person's ability to manage their underlying diabetes, such as monitoring glucose levels, operating an insulin pump, taking medication, cooking a healthy meal, and reading educational materials. Those participants with limited or no access to specialised technology for people with vision impairments relied on family members or others for assistance, or neglected recommended practices.



Individual with diabetes,
age 53, Germany

“The pump I use is not barrier-free. I can trigger a bolus on my own, this is of course the minimum that you should be able to do. I can recognise if the reservoir is almost empty, or if the battery is low. That’s what I can see from the pump, not see but hear from the beeping sound of the pump. Everything else I let my daughter handle, she can see.”



Individual with diabetes,
age 88, Japan

“I can’t see well, so I do not recognise the gauge for injections. If someone fixes the gauge for the units, I do injections myself.”



Engagement in Care: Predictors and Practice

Diabetes Diagnosis

A diabetes diagnosis is the obvious antecedent to concerted action regarding DR. However, reports from participants with diabetes and from providers suggest a relatively frequent late diagnosis of diabetes. Many participants were already symptomatic (e.g., excessive thirst, weight loss, pain in the extremities) when they were diagnosed. For a substantial minority, diabetes was only identified once complications, including vision impairment, had occurred.



Diabetes specialist,
Argentina

“The patient gets used to the symptoms, has complications, and detects the illness through his complications. Ten to fifteen percent of patients detect their illness through the complications—for example, retinal complications. And the lower their socioeconomic status, this form of access to diagnosis becomes more frequent.”

Knowledge and Awareness

Basic knowledge regarding the causal relationship between diabetes and retinopathy was relatively high, which may in part reflect the fact that two-thirds of those interviewed had already been diagnosed with DR. Still, there were a number of respondents, approximately 20%, who were unaware that vision loss can be a complication of diabetes, or had been unaware until they faced vision issues themselves.



Individual with diabetes,
age 32, Bangladesh

“I can’t see properly, everything looks blurry, my eyes seem burning. I didn’t know that eye diseases were linked with diabetes.”

Even where individuals did know about the relationship between diabetes and eye complications, details regarding the risk, and how to avoid eye disease, were not always clear.



Individual with diabetes,
age 28, Argentina

“Well, I don’t know much, but I do know that in the long term you may have problems, see less, and even lose your vision. But why exactly that happens, I don’t know...or when that could happen to me, I don’t know. I understand that if you have your sugar levels high for a long time, you will eventually have problems with your vision and lose your cells or something.”



Phase I: Qualitative Study

Information Sources

For people living with diabetes who were aware of the risk of DR, the information came from a variety of sources. Many, but not all, described being informed by their primary care provider or diabetes specialist. Others learned about the connection between diabetes and vision issues from family or peers also affected by diabetes, and from the Internet and television. Still others learned about the connection from eye specialists, but only after the onset of vision loss symptoms.



Individual with diabetes,
age 40, Japan

“Well, I learned through education when I was admitted to the hospital, watched several DVDs, and now I understand that there are three complications, eyes, foot, and kidney can be affected.”



Individual with diabetes,
age 50, Mexico

“Well, I just know that if you don’t control your diabetes, you can lose your sight... [I learned this] through other diabetics, some of them have even lost their vision”



Individual with diabetes,
age 55, Saudi Arabia

“Honestly, my major source is the Internet. I search for the information there, and most of the time I find the needed information. Sometimes, I read the booklets provided by the hospitals. My other source is the doctor.”

Vision Screening

For some with an increased knowledge regarding risk of vision impairment and blindness they were then more motivated to engage in regular screening.



Individual with diabetes,
age 57, Japan

“It is very important for me. If I go blind, it is a huge problem. I think I need to have regular detailed check-ups.”

However, a number of participants acknowledged that even though they knew about the connection between diabetes and vision loss, they were insufficiently motivated to visit an eye specialist in the absence of noticeable symptoms.



Individual with diabetes,
age 60, Saudi Arabia

“Yes, he told me frankly, that I should go and examine my eyes and meticulously follow up with the ophthalmologists. However, as I mentioned, I did not obey at the beginning. Sometimes, I would lie to him and say, “Yes, I did.” Only when I felt a problem I started following up meticulously.”



Individual with diabetes,
age 61, Mexico

“Well they had told [my husband and me] about the eyes, but we hadn’t thought about it worsening as time passes, because one does not take care of oneself exactly how they tell us to do it, until afterwards.”

Provider Referrals

Primary care providers and diabetes specialists in the study described regularly referring their patients to eye specialists. However, and consistent with the information above, they felt that many of their patients with diabetes did not comprehend the importance of eye screening and were not motivated to visit an eye doctor prior to the development of impairment. They reported that their patients did not understand that a person may have asymptomatic DR and that early treatment could reduce the risk of vision loss.



Ophthalmologist, Romania

“We are trying to draw their attention to the need of periodic ophthalmologic examinations. But unfortunately, we do not succeed 100% every time. A lot of our patients do not understand why they should come, even if they do not have anything with their eyes. “Why should I come?” they ask us. “Nothing upsets me,” they say.”

Phase I: Qualitative Study

“Those who were referred, they do not come until they are not able to see.

Otherwise, they say that I was told five years ago, but I was seeing, I did not come. They wait for vision problems, then come.

For DR it is late.”

Ophthalmologist, Uganda



Individuals with diabetes described a range of referral practices, including some that linked patients with specific affiliated providers. However, a number of individuals with diabetes described relatively vague recommendations regarding eye care, rather than concrete referrals to specific clinics or specialists.



Individual with diabetes,
age 28, Argentina

“We talked about [eye problems] before and she just reminds me to get my eyes checked.”



Individual with diabetes,
age 60, Saudi Arabia

“During the visits, he always ask me about my vision, he doesn’t examine my eyes, or sometimes just look at my eyes externally, and just reminds me that I should be following up with the ophthalmology clinic.”

There were suggestions that inadequate referrals to ophthalmology services resulted from insufficient information. Providers may know the general connections between diabetes and DR, but may not have sufficient information regarding disease progression and risk to translate that into good practices.



Photo: Maria del Carmen Escobar Landaverde



Primary care provider,
Japan

“Complications of diabetes affects eyes, kidney, and peripheral nerves, [providers] all know that. But say, guidelines, how often do we need to follow up the patient or such specific information on interventions. There are a lot of doctors who understand we should do this, and we share the same image, but not in details, specific steps how.”



Ophthalmologist, Romania

“First of all they do not know how to send patients, or they do not recommend that the patient goes to a specialist.

Because, unfortunately, the diabetologists and sometimes even our ophthalmology colleagues are pleased with prescribing only eyeglasses, without doing examination of the eye fundus.”

Among providers seeking to refer patients to ophthalmologists, the most common complaint focused on insufficient access to services. However, referral pathways may also be complicated, as described by a diabetes specialist in Mexico.



Diabetes specialist, Mexico

“Generally, the ophthalmology department does not allow referrals directly from us within this hospital.

They must be sent from a family medicine clinic.

So, for example, when I see a patient with diabetic retinopathy, I have to send them once again to see his family doctor, so he can be sent to the ophthalmologist from there.”

Phase I: Qualitative Study



Treatment of Diabetic Eye Disease and Diabetic Macular Edema

Many participants who experienced vision impairment described the various treatments they have undergone in an effort to slow or reverse the impact of DED. A number of successes were reported.



Individual with diabetes,
age 63, Romania

“I can see how my vision gets better. So, I saw only pink, and after laser, I start to see perfect and clear. So, I think, that it is one of the greatest achievements. I mean this treatment with laser.”



Individual with diabetes,
age 56, Saudi Arabia

“The doctor ... decided to give me an injection with a drug that would help relieving the edema. Finally, he showed me some red dots in the picture [of the eye]. And now, after this treatment, the picture was much better, and he was so happy for the results.”



However, several participants who received treatment for DR or DME described suboptimal outcomes and the need for additional care. It should be noted that, when applicable, most participants continued treatment.



Individual with diabetes,
age 59, Bangladesh

“[My eyes have] been examined; I took laser treatment in both eyes two times. But it was not good and I had to examine my eyes again and got five injections in both eyes. Then I was diagnosed with cataracts, had operation, now I have to wear lens.”

Even without complications, certain treatments for eye disease requires repeat visits to the doctor and can be a burden to individuals, which in turn may deter them from receiving appropriate care.



Ophthalmologist, Japan

“Patients with diabetic retinopathy or diabetic macular edema who need treatment require frequent clinic visits, but they are the working generation..., so they cannot take a day-off for this. ...they have difficulty in visiting clinic. And say laser treatment or anti-VEGF treatment for diabetic macular edema cost quite a lot, and that makes patients hesitate to have treatment, ...not all cases, but some,... so that can be a barrier to the services.”

In most countries, ophthalmologists reported a range of treatment options available.



Ophthalmologist, Romania

“We offer exactly the same medical care for DR and for DME as would be offered all over the world. The injection with triamcinolone and the injection with anti-VEGF, we cannot administer here, but we work together closely with our colleagues from the hospital, where it can be done.”

“If patient needs laser treatment we provide it. If patient develops edema and needs a vascular endothelial growth inhibitor injection, we have all this facility.”

Ophthalmologist, Bangladesh

Provider concerns regarding treatment were varied and included: the high cost of treatment, the lack of coverage for particular services, equipment shortages, insufficient guidance regarding optimal treatment, standard protocols, and difficulties treating patients who have a poor understanding of their illness, as well as those presenting for care too late, with poorly controlled diabetes, and/or with multiple co-morbidities.



Ophthalmologist, Mexico

“Retinal surgery is difficult, expensive, and also does not always provide the satisfactory results the patient would like. Perhaps we as medical professionals end up satisfied, but the patient will not have the level of vision he thought he would have. They are patients who are sick, patients who have internal problems, and they come to us when their condition is very serious.”

Phase I: Qualitative Study



Coordinating Care

For individuals with diabetes undergoing eye treatment, the need for multi-directional communication, involving the patient, the primary care provider, and the ophthalmologist was recognised by many as an ongoing need.

Processes for maintaining communication varied. Some providers relied on patients to convey medical information themselves; they specifically asked patients to bring written reports from other medical visits or more casually asked about care received.

Others described direct and regular contact with colleagues, including exchange of test results and collaborative treatment planning. This type of communication was facilitated by systemic factors, including co-location of a multidisciplinary team and electronic health records.



Primary care provider,
Germany

“What can be a problem sometimes, depending on where we send them, like eye specialists, we get more or less feedback...there are standardised forms that [aren’t] much trouble and that we get from a lot of eye specialist practices, but not always. Then you have to ask the patients themselves if he has been to the eye specialist and then the statement is not always very correct and reliable. This can be a problem then ... you don’t exactly know if the patient has a problem or not.”



Primary care provider,
Romania

“There is a good collaboration between us and the specialists. We talk on the phone and I can obtain an appointment for my patients by them. I think that we work together without any kind of problem. I have to say the same about ophthalmologists, too.”

A number of patients were unsure if there was communication between their providers. They guessed that it might occur, but apparently had no specific evidence, and expressed no particular concerns. Among those that did know about communication, good communication was, not surprisingly appreciated, and poor communication was criticised. From the patient perspective, factors impacting communication and coordination of care included provider motivation and pre-existing connections between physicians.



Individual with diabetes,
age 56, Saudi Arabia

“What I really miss is the real link between the doctors. Everyone is just interested in his own topic, and that’s it.

Yes, they warn about other issues, but maybe once and that’s it. They never follow up.”



Individual with diabetes,
age 50, Mexico

“My son has been very helpful. He is the one that also helps me buy things. If I get really bad, he takes me to the doctor. Right now, he’s asking me a lot of details about my diabetes. I guess the person that he’s talking to is asking him all of those things.”



Individual with diabetes,
age 61, Romania

“[My doctor] collaborates with my wife too, when I used to work and I had to go every three months to periodic examinations. And often my wife used to go in my place to take out the medications because my boss told me that I need to use a vacation day every time for this.”



Supportive Services

Support for people living with diabetes overwhelmingly came from unpaid caregivers such as spouses, children, parents, siblings and friends. These individuals provided assistance with activities of daily living and disease management, including keeping track of doctors’ appointments, transportation to the clinic visits and, in some cases, attending the doctor’s appointment in place of the patient.



Phase I: Qualitative Study

Participants from Germany, Argentina, and Mexico mentioned support services such as peer groups, provided through an established organisation. Although some peer groups focused on diabetes management (e.g., dietary behaviour, physical activity, medications), others worked with patients on how to best live with vision loss. Participants and professionals that were engaged with support groups described their experience positively, noting the use of information provided by professionals and peers, as well as the interpersonal connections.



Individual with diabetes,
age 59, Germany

“I am working with a computer with voice output and I retrieve a lot of information through the Internet. I also have a support group where information is exchanged... Especially the support group I find very important.”



Diabetes educator,
Argentina

“If the patient has a family that supports him or her it’s one thing, but when there is not enough support in the family, being part of group makes up for it. This is what occurs with our patients that have retinopathy and those that are blind. The group is extremely important for them. They enjoy themselves a lot when they are together. They talk, they tell stories, and they talk about the stuff they get. We learn from them. They tell us “At this place they give us test strips”, “There’s a new type of device”, and things like that, and they all pass that information around among themselves.”

Diabetes education outside of support groups (and outside the regular physician visit) was provided on a one-to-one basis or in workshops, usually immediately following diagnosis. Very few individuals with diabetes reported ongoing contact with diabetes educators. Similar to the groups described above, vision issues were included within the educational curricula, but generally not emphasised.



Diabetes specialist,
Bangladesh

“We provide retinopathy related information to our patient via our diabetes educators.

When diabetes educators teach them about diabetes, at the same time they also teach them about diabetes retinopathy and macular edema, though it is not the whole information about retinopathy or macular edema, but we try to serve them.”



Systemic Barriers and Facilitators to Care

Not surprisingly, health care delivery systems differed considerably within the eight countries, with better access to comprehensive care in the highest income countries of Germany and Japan. In the remaining countries, access to some or all services was problematic for at least a portion of the population, with the location of clinics and hospitals and costs of care being uppermost in the minds of patients and their families.

Availability of services

Individuals with diabetes and providers in high-income countries reported that services are widely available, with most people able to access eye care in close proximity to their homes.



Primary care provider,
Germany

“The concentration of eye specialists is high enough ... Here in the region we have very good coverage with specialised centres with the clinics in Heidelberg and Mannheim where they provide the newest methods. So there is a very good access for the treatment to eye specialists.”

In the middle and lower income countries, greater limitations were described, with the most specialised services available in larger cities, at major hospitals and universities or other select locations.



Diabetes specialist,
Romania

“There is a disadvantage living in a small town, because the departments are not equipped with the necessary devices, and there is lack of doctors and specialists. Patients should be sent to the university centres, in order to be treated for the complications of diabetes.”

Phase I: Qualitative Study

“Of the 20 ophthalmologists in Buenos Aires, there are only two places that can treat retinopathy.”

Diabetes educator, Argentina

Shortages were attributed to gaps in trained personnel, as well as the cost of medications, supplies, and equipment.



Ophthalmologist, Uganda

“The equipment is expensive. This has always been the challenge. That has been one of the de-motivating issues. So [providers] know that if they train, some may not get the equipment.

The lasers are not many. Mengo has one, and Mulago has another.”



Individual with diabetes,
age 60, Saudi Arabia

“The doctor then told me that I need laser shots and intra-ocular injections. However, the drug is not available, and that I need to go to Riyadh (the capital) to get it. Then, I decided to go to Jordan instead because it was more convenient to me in terms of time and money.”

Wait Times

The issue of a high volume of patients and demand for services and long wait times to see an eye specialist, for an appointment and on the day of the visit, was commonly mentioned by both those with diabetes and providers. These barriers to care were most pronounced in certain middle income and lower income countries with a significant lack of providers.



Individual with diabetes,
age 50, Mexico

“People tell you to go get “Seguro Popular” (government subsidised insurance) but one has to go to the clinic at 3:00 in the morning to be able to get a number, because it’s so busy. And you can’t imagine what that’s like for someone with diabetes.”



Individual with diabetes,
age 56, Uganda

**“You wait for long hours.
Even if you come early, there
are always people. I wonder
whether some sleep here.”**

One provider from Mexico said that the long wait to see an ophthalmologist could delay care, allowing the eye disease to progress needlessly.

Cost and Payment

Despite systems with health care coverage and/or free care, some out of pocket payments were required for insurance premiums to see particular providers, or to access certain treatments, medications and/or supplies (e.g., test strips).

Some patients also have an additional transportation cost to attend an appointment which may be cancelled at the last minute or be significantly delayed. Cost and payment issues impacted treatment for DR, particularly in middle and lower income countries, where institutional resources are scarce and patients struggle just to meet basic needs.



Individual with diabetes,
age 50, Romania

**“Each of [my eye medications]
costs a lot to me. I have taken
three months of them, then
I simply left them out,
because I could not afford
it anymore.”**



Ophthalmologist, Mexico

“[Patients] wait an irrational amount of time. There are patients who cannot get an appointment until four, five, six months later or more, in order to be seen when their condition must be treated as soon as possible.

I think this is the main obstacle patients’ face—there are too many patients, and they can’t all be seen in a timely manner.”

Phase I: Qualitative Study

“Some of these patients we will recommend an injection, which is quite expensive. Not every person or the hospital cannot afford it. So they are not accessing it.”

Diabetes educator, Uganda

In a small number of instances, both patients and providers reported that in order to decrease costs to their patients, services were offered at a discounted price, or providers negotiated with colleagues to make expensive treatments accessible to those who could not afford them.



Individual with diabetes,
age 52, Argentina

“The doctor would charge me say, out of 10,000 pesos he would charge me 2,000. He currently sees me without charging me—he makes no business with me at all.”



Ophthalmologist, Romania

“If it is suspected that there would be a maculopathy, personally I try to send patients to an OCT investigation, because I do not have an OCT in the clinic, but I find a solution to everybody. Even for the ones with little money, I send him somewhere, where based on a recommendation letter from me or from the family doctor; it can be made free of charge, because it is very important.”

Travel

Going to and from the doctor, the hospital for diabetes treatment and ophthalmological services was an ongoing challenge for several participants. Furthermore, many patients have complex comorbidities and with this the need to attend many specialist appointments. Both the distance and the cost of travel becomes a burden and a deterrent to accessing care, particularly for those outside of urban centres.



Primary care provider,
Mexico

“Someone from Jilotepec, for example, who has to go to the general hospital (3 hours or more to get there) and If she/he needs high specialty attention, he/she needs to go back to the town, and after that they need to go to the high specialty hospital that is even farther (2 or more hours after the general hospital), the transport cost is higher.

If someone needs to be hospitalised or has a long treatment, a relative needs to stay in a near hotel or even in the street.”



Diabetes educator,
Argentina

“And I am only 30 kilometers away, [but] it is another world. It is difficult for people to transport themselves to these centres from where doctors can treat retinopathies.”



Phase I: Qualitative Study



Discussion

Phase I of the DR Barometer Study describes in very real ways the often-devastating impact of DR and vision impairment on the lives and livelihood of the person with the condition and their family. This qualitative study also highlighted important factors associated with screening, treatment, and disease self-management from the perspectives of providers.

Timely detection and proper management of diabetes reduces the risk of DR^{3,24} and facilitates its early detection.¹¹ However, diabetes can be asymptomatic for years, or its symptoms may appear gradually, so those affected may not recognise changes in their health.^[25] Reports from providers and individuals with diabetes in this study suggest that late diagnosis is common, particularly in lower income countries. The literature also indicates problematic delays in diabetes diagnosis and poor disease management, particularly in low income countries and among socioeconomically disadvantaged populations.^{11,26,27}

Although detection and management of diabetes per se are not the focus of the report, it is essential that these be addressed, with education, access to services, and high quality care, for prevention and optimal management of DR.

Consistent with the literature,^{12,18} many participants with DR and impaired vision reported serious negative impacts, including: job loss and resultant economic hardships, limitations on driving and travel, autonomy

and the ability to be involved in social and recreational activities, and challenges to disease management, including self-monitoring and the use of medical services.

Patients described in graphic ways the psycho-social implications of changes in their capacity which only highlights the importance of prevention, screening and early management. There is a real and urgent need for supportive services, to improve quality of life and reduce the risk that disease-related stress will exacerbate with poor diabetes self-management.²⁸

Barriers to Screening: Inadequate Awareness, Motivation, and Direction

Some adults with diabetes were not aware of the link between diabetes and vision loss, or had been unaware prior to the onset of symptoms. A portion of those that were aware of the link, said that the new knowledge had motivated them to seek regular screening. On the other hand, other participants ignored recommendations regarding eye care prior to the onset of symptoms.

The published literature cites inadequate knowledge and motivation as impediments to screening, particularly for individuals with lower socioeconomic status.²⁹ Recommendations for addressing these impediments include increased and tailored (e.g., language appropriate)²³ outreach to individuals with diabetes,¹⁹ easier access to screening (e.g., telemedicine, mobile units)^{30,31} and better integration of screening services with primary care and diabetes care,³² so that patients may access eye care in course of a periodic visit.

In addition, where available, information from diabetes support groups and diabetes educators was considered valuable and these services may also be mobilised to increase knowledge, motivation, and use of screening services.

Eye specialists in a number of countries criticised providers treating diabetes for delayed referrals, which some attributed to insufficient knowledge regarding the specifics of DR.

The development and promulgation of clear guidelines has been recommended and where electronic health records are used, embedded decision supports may help to address this gap.⁽¹⁹⁾ In addition, continuing education opportunities for health care professionals should be enhanced in order to ensure providers are current on the latest standards of care. A common problem reported among the providers was nonspecific referrals rather than a more directed approach that includes connections to specific providers and proactive approaches to treatment, which includes scheduling appointments.

Barriers to Treatment and Care

Individuals with diabetes and providers noted a number of barriers to care for DR, particularly in middle and lower income countries. These barriers include extensive wait times for appointments and on the day of a visit, out of pocket costs for health insurance premiums, medical visits, treatment, and supplies, and the concentration of services in urban areas or university centres, necessitating travel for those living elsewhere.

Consistent with the literature,^{21,22,33} each of these was reported to impact the use of services, particularly for low-income populations within these countries, making the control of diabetes and DR more difficult and in turn discourages adherence to medical recommendations. It is no surprise that, compared to high income countries, lower income countries generally have a less robust health infrastructure, including fewer providers per capita, less well-equipped facilities, and fewer resources to offset patient costs.^{22,34}

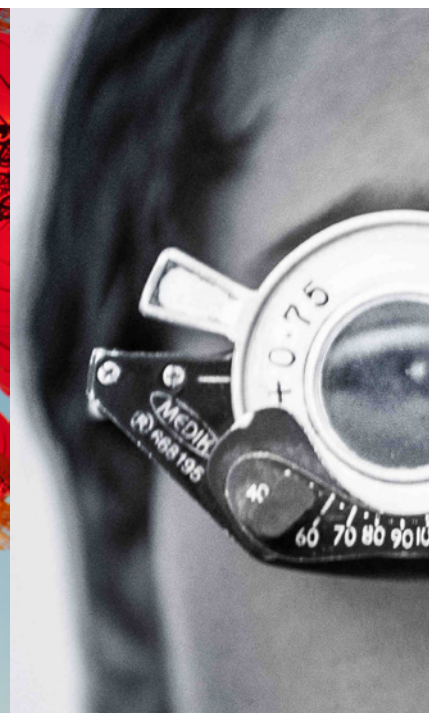
Similarly, it is not surprising that disparities exist within countries, with significantly greater barriers to care among socioeconomically disadvantaged populations.^{29,35,36} Addressing these barriers, which manifest themselves at the patient level, requires policy solutions²² that build from current best practices, and that take into account the substantial repercussions of inaction and include targeted programming, particularly for socioeconomically disadvantaged populations.^{5,36}

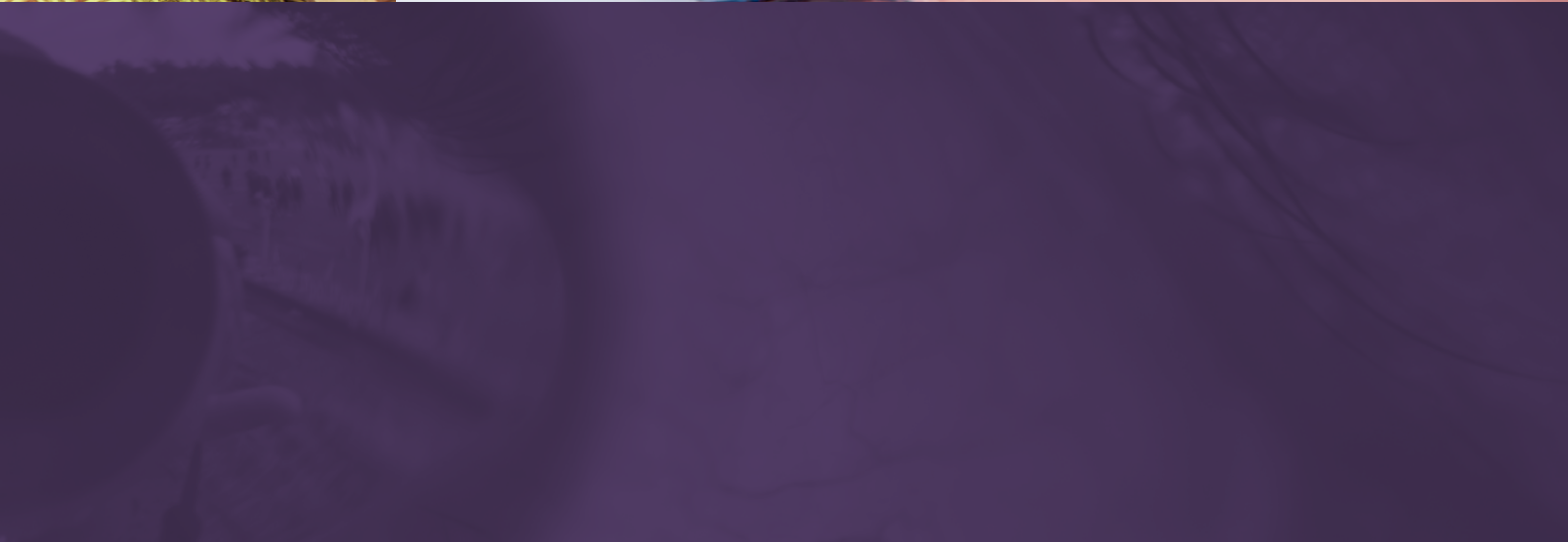
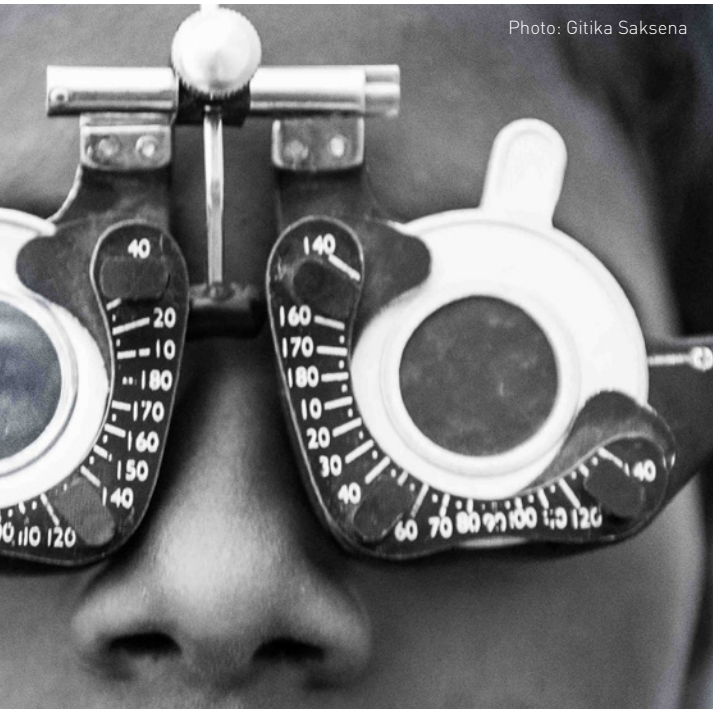
Limitations of the study

This study has a number of limitations. Although a sample size of 121 is relatively large for a qualitative study, given the diversity of respondents (eight countries, individual with diabetes as well as health care professionals), it is too small to draw definitive conclusions.

Furthermore, the need for a consistent research protocol across all countries precluded in-depth exploration of particular local level issues. In addition, the sample is not representative as participants were most often recruited through the providers and diabetes organisations, so were likely to be more engaged in care than others with diabetes and DR. Their perceptions and experiences may not be consistent with the experiences of their compatriots.

Finally, although in-country interviewers were selected based on relevant experience and all received training on the research protocol, the results were variable, and some interviewers were more successful in engaging participants in a rich and nuanced conversation, as compared to others.







44%

of all providers **did not have, or did not use, written protocols** for the management of diabetes-related vision loss



Phase II: Quantitative Results

The Diabetic Retinopathy (DR) Barometer Study sought to assess the awareness of diabetic eye disease (DED) and access and barriers to diabetes management, including screening for DED and timely treatment. In the context of this study, DED comprises diabetic retinopathy (DR) and diabetic macular edema (DME).

The results from this survey provide new evidence reflecting concerns from the voices of thousands of adults 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.

The DR Barometer Report describes the findings from a purposeful sample of adults with diabetes (patients) and health care professionals (providers) across 41 countries who participated in the study. Respondents from each country were grouped into regions as defined by the World Health Organization (WHO) and into the World Bank Income Groups (WBIGs).

Key Demographic Characteristics

Adults with Diabetes

There were 4,340 adults with diabetes (patients) who responded to the survey. Fifty percent (n=2,163) were from the European region, 21% (n=909) from the Western Pacific region and 20% (n=865) from the Region of the Americas, with the remaining 9% (n=403) from the three other WHO regions (the Eastern Mediterranean region 6% (n=261), the African region 1.8% (n=78), and the South-East Asia region 1.5% (n=64)). Sixty percent of patients were from high-income economies and 36% from upper-middle-income economies (see Figure 5.1).

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

Seventy-three percent (n=3,161) of respondents had no reported evidence of DED or DME. Twenty percent (n=847) reported a diagnosis of DED, and a further 7.6% (n=332) had DME. In the European region, 20% (n=424) of respondents had DED and 8.9% (n=193) had DME. In the Region of the Americas, the reported frequency of DED and DME amongst respondents was 19% (n=167) and 6.4% (n=55), and in the Western Pacific Region was 19% (n=173) and 5.6% (n=51), respectively.

Phase II: Quantitative Results



Type 2 diabetes was the most prevalent (54%) amongst respondents and 37% were diagnosed with type 1 diabetes. A further 9.2% were either unsure or did not know their type of diabetes. Just over half of the respondents (54%) were female, 26% were between 18 and 39 years of age, 38% were 40-59 years of age, 33% were 60-79 years of age, and the remaining 2.6% were 80 years of age or older (see Table 5.1).

Half of the respondents were diagnosed with diabetes more than 10 years ago, with 22% being diagnosed 21 years ago or more. Twenty-eight percent of respondents felt that their diabetes was not well controlled.

With increasing age, there were a greater proportion of adults who had type 2 diabetes compared with those with type 1 diabetes. Amongst 18 to 39 year-olds, 74% had type 1 diabetes and 21% had type 2. In the 40-59 year age group, 30% had type 1 and 61% had type 2 diabetes and 71% of respondents 60-79 year-olds had type 2 diabetes with only 18% having type 1.

The proportion of people with DED and DME also increased marginally with age. Amongst 18-39 years, 18% had DED and 6.8% had DME. This remained somewhat steady in the 40-59 year age group with 19% having DED

and 6.5% with DME, and then increased to 21% for DED and 9.1% for DME in the 60-79 year age group. In those aged 80 years or older, 21% had DED and 15% had DME.

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

In the first year since diagnosis, 11% of respondents had DED and 4.6% had DME. In those diagnosed one to five years ago, 8.7% had DED and 5.5% had DME whilst 13% and 5.3% of people diagnosed between six and ten years ago had DED and DME, respectively.

These proportions rose to 19% for DED and 7% for DME for people diagnosed between 11-15 years ago and then to 24% and 8.4% for those diagnosed between 16 and 20 years ago. A further increase was observed for people diagnosed 21 years ago or more with both DED and DME escalating to 40% and 14% respectively.

For those who reported their diabetes was well controlled, 20% had DED and 7.7% had DME. In those who felt their diabetes was not controlled 24% had DED and 9.5% had DME.

Table 5.1: Summary of key characteristics of adults with diabetes

Group	Subgroup	All respondents	Type 1	Type 2 diabetes	With DED	With DME
All respondents		4,340 (100%)	1,611 (37.1%)	2,326 (53.6%)	847 (19.5%)	332 (7.6%)
Gender	Male	1,737 (46.2%)	525 (30.2%)	1,045 (60.2%)	347 (20.0%)	137 (7.9%)
	Female	2,022 (53.8%)	869 (43.0%)	971 (48.0%)	477 (23.6%)	186 (9.2%)
	Total Missing	581	217	310	23	9
Age	18-39 yrs	1,144 (26.4%)	842 (73.6%)	234 (20.5%)	205 (17.9%)	78 (6.8%)
	40-59 yrs	1,667 (38.4%)	496 (29.8%)	1,020 (61.2%)	317 (19.0%)	108 (6.5%)
	60-79 yrs	1,415 (32.6%)	253 (17.9%)	999 (70.6%)	301 (21.3%)	129 (9.1%)
	80 yrs and over	114 (2.6%)	20 (17.5%)	73 (64.0%)	24 (21.1%)	17 (14.9%)
Time since diagnosis	Within the last year	329 (7.7%)	82 (24.9%)	176 (53.5%)	37 (11.2%)	15 (4.6%)
	1 - 5 years ago	963 (22.6%)	220 (22.8%)	623 (64.7%)	84 (8.7%)	53 (5.5%)
	6 - 10 years ago	806 (18.9%)	178 (22.1%)	552 (68.5%)	106 (13.2%)	43 (5.3%)
	11 - 15 years ago	699 (16.4%)	225 (32.2%)	422 (60.4%)	129 (18.5%)	49 (7.0%)
	16 - 20 years ago	513 (12.0%)	216 (42.1%)	263 (51.3%)	121 (23.6%)	43 (8.4%)
	21 years ago or longer	918 (21.5%)	665 (72.4%)	227 (24.7%)	364 (39.7%)	125 (13.6%)
	Don't know/ Not sure	39 (0.9%)	7 (17.9%)	17 (43.6%)	4 (10.3%)	3 (7.7%)
	Total Missing	73	18	46	2	1
Control of Diabetes	Controlled	2,787 (69.3%)	1,038 (37.2%)	1,491 (53.5%)	559 (20.1%)	215 (7.7%)
	Not controlled	1,140 (28.3%)	435 (38.2%)	607 (53.2%)	272 (23.9%)	108 (9.5%)
	Don't know/ Not sure	97 (2.4%)	25 (25.8%)	56 (57.7%)	8 (8.2%)	7 (7.2%)
	Total Missing	316	113	172	8	2

NB [1]: There was some missing data (not all respondents provided responses to every question). Percentages for the first row and column are calculated using the total number of respondents less the number of missing values as the denominator. All other percentages are calculated using the total on the corresponding row of the first column as the denominator.

NB [2]: The group with DED excludes all people with DME

Adults with diabetes by country and region

Global Adults with Diabetes (n=4,340)

Region of the Americas

865 countries (20%)

- Argentina (123)
- Brazil (139)
- Canada (58)
- Chile (21)
- Colombia (134)
- Costa Rica (74)
- Mexico (307)
- Venezuela (9)

(Figure 5.1)

- World Bank Income Group: High-income economies
- World Bank Income Group: Upper-middle income economies
- World Bank Income Group: Low-income or Lower-middle income economies

European Region

2163 countries (50%)

- | | |
|----------------------|------------------------|
| ● Bulgaria (30) | ● Poland (111) |
| ● Czech Republic (5) | ● Portugal (73) |
| ● Denmark (135) | ● Romania (127) |
| ● Finland (86) | ● Russia (113) |
| ● France (88) | ● Slovenia (64) |
| ● Germany (290) | ● Spain (97) |
| ● Ireland (84) | ● Sweden (79) |
| ● Italy (71) | ● Turkey (426) |
| ● Netherlands (79) | ● United Kingdom (134) |
| ● Norway (71) | |

Eastern Mediterranean Region

261 countries (6%)

- Algeria (68)
- Egypt (80)
- Lebanon (1)
- Saudi Arabia (44)
- United Arab Emirates (68)

South East Asia Region

64 countries (1.5%)

- Bangladesh (64)

African Region

78 countries (1.8%)

- South Africa (70)
- Uganda (8)

Western Pacific Region

909 countries (21%)

- Australia (321)
- China (75)
- Hong Kong (256)
- Japan (77)
- Malaysia (110)
- South Korea (70)

Health care professionals by country and region

Health Care Professionals (n=2,329)

Region of the Americas

536 countries (23%)

- Argentina (27)
- Brazil (124)
- Canada (120)
- Chile (31)
- Colombia (158)
- Costa Rica (12)
- Mexico (57)
- Venezuela (7)

(Figure 5.2)

- World Bank Income Group: High-income economies
- World Bank Income Group: Upper-middle income economies
- World Bank Income Group: Low-income or Lower-middle income economies

European Region

2163 countries (50%)

- | | |
|-----------------------|------------------------|
| ● Bulgaria (10) | ● Poland (42) |
| ● Czech Republic (15) | ● Portugal (73) |
| ● Denmark (7) | ● Romania (127) |
| ● Finland (8) | ● Russia (113) |
| ● France (47) | ● Slovenia (64) |
| ● Germany (75) | ● Spain (97) |
| ● Ireland (39) | ● Sweden (79) |
| ● Italy (49) | ● Turkey (426) |
| ● Netherlands (17) | ● United Kingdom (134) |
| ● Norway (15) | |

Eastern Mediterranean Region

246 countries (11%)

- Algeria (158)
- Egypt (21)
- Lebanon (11)
- Saudi Arabia (24)
- United Arab Emirates (31)

South East Asia Region

32 countries (1.4%)

- Bangladesh (32)

African Region

85 countries (3.6%)

- South Africa (68)
- Uganda (17)

Western Pacific Region

382 countries (16%)

- Australia (141)
- China (86)
- Hong Kong (44)
- Japan (44)
- Malaysia (50)
- South Korea (17)

Phase II: Quantitative Results

Health Care Professionals

There were 2,329 health care professionals (providers) who responded to the survey. Forty-five percent (n=1,048) were from the European region, 23% (n=536) from the Region of the Americas, and 16% (n=382) from the Western Pacific region, with the remaining 16% (n=363) from the three other WHO regions (the African region, the South-East Asia region, and the Eastern Mediterranean region). Fifty-two percent (n=1,216) of providers were from high-income economies and 45% (n=1,043) were from upper-middle-income economies (see Figure 5.2).

Amongst the providers, 37% (n=855) were ophthalmologists, 17% (n=403) were diabetes specialists, and 16% (n=365) were primary care providers. The remaining respondents were optometrists, nurses, health educators or other types of professionals.

Ophthalmologists comprised both general ophthalmologists and retinal specialists. There was a similar proportion of ophthalmologists in high-income economies (36%, n=441) and upper-middle income economies (38%, n=397).

The majority of providers (89%) had their main practice in an urban setting. Forty-seven percent practised in the government sector whilst almost a third (29%) had their main practice in the private sector, 15% in a combined or mixed sector, and 8% in the non-profit sector.

Almost half (49%) of ophthalmologists had their main practice setting in hospitals and 46% in eye clinics whereas 45% of diabetes specialists practised primarily in diabetes clinics and 37% in hospitals. The majority of primary care providers were in general medical practice (72%) and a further 13% in hospitals.

On average, providers had been practicing for 16 years and 72% had completed graduate or advanced degree education.

Knowledge and Management of Diabetes

Adults with Diabetes

The majority of patients (94%) saw a healthcare professional for their diabetes, 60% saw a diabetes specialist and 34% a general practitioner. On average, respondents saw their provider between four and five times per year.

Adults with diabetes were informed about their condition through a range of sources. Eighty-five percent received information from their doctor or nurse, 43% via the internet, 37% from a diabetes or other health organisation, and 34% from a nutritionist or dietitian.

In comparison, only half of the respondents received information, specifically about DR and DME, from their doctor or nurse, 23% via the internet, and 20% from a diabetes, or other health organisations. In those who did not receive information from any of the traditional sources, there was only 1.3% who did not receive general diabetes information, compared with almost a third (31%) not receiving any information on DR or DME (see Table 5.2).

Table 5.2: Source of information about diabetes and DED

Sources	Information on Diabetes (n=4,150)	Ophthalmologists (n=3,682)
Doctor or nurse	3,544 (85.4%)	1,850 (50.2%)
Internet	1,764 (42.5%)	832 (22.6%)
Diabetes or other health organization	1,535 (37.0%)	744 (20.2%)
Nutritionist or dietitian	1,419 (34.2%)	NA
Health educator	1,020 (24.6%)	411 (11.2%)
TV / Radio / Newspaper / Magazines	991 (23.9%)	393 (10.7%)
Family / Friends / Neighbors	910 (21.9%)	250 (6.8%)
Social media (e.g. Facebook, Twitter, blogs)	742 (17.9%)	NA
Pharmacist	444 (10.7%)	NA
Other	26 (0.6%)	15 (0.4%)
None of the above	56 (1.3%)	1,128 (30.6%)
Other	26 (0.6%)	15 (0.4%)
None of the above	56 (1.3%)	1,128 (30.6%)
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%)

NB [1]: Sources marked NA were not included in the question.

NB [2]: The group with DED excludes all people with DME

A range of strategies was used by patients to manage their diabetes. For those with type 1 diabetes, apart from insulin, 55% managed their diabetes with diet, 42% with exercise, 16% with oral medicines, and 5% with natural or herbal medicine. For those with type 2 diabetes, 75% reported that they managed their condition with oral medicines, 71% with diet, 46% with exercise, 39% with insulin, and 8% with natural or herbal medicine.

Respondents reported numerous challenges in controlling their condition, some of which they had personal control over and others were a result of the inflexibility or inadequacy of the health system and external factors. From the perspective

of personal responsibility, the main challenge was related to diet, where 44% of respondents said it was too hard to eat the right things. One in five (21%) had competing priorities, did not want to think about having diabetes (16%), or said they did not know enough about their diabetes (11%).

External factors were also prominent barriers with more than a quarter (26%) of respondents reporting the high cost of care, long wait times for an appointment to see my doctor or specialist (24%), difficulties in travelling to the appointment (17%), and a reported lack of available health services (11%) (see Table 5.3).

Phase II: Quantitative Results

Table 5.3: Barriers to diabetes management

Challenge	(n=3,994)
Too hard to eat the right things	1,774 (44.4%)
High cost of care	1,054 (26.4%)
Long wait time for an appointment to see my doctor or specialist	968 (24.2%)
Too many other things to do	845 (21.2%)
Travel to my regular doctor or specialist is difficult	687 (17.2%)
Don't want to think about having diabetes	621 (15.5%)
Health services needed are not available	449 (11.2%)
Don't know enough about diabetes	444 (11.1%)
No insurance	357 (8.9%)
Stigma or discrimination because of diabetes	298 (7.5%)
Other	476 (11.9%)
None of the above	577 (14.4%)
Eye exams are not important	4 (2.0%)
Clinics are too small or lack necessary equipment/staff	4 (2.0%)
Other	33 (16.1%)

Over 92% of respondents had undergone blood glucose, urine, blood pressure and weight checks, most of which had occurred within the last year (83% – 92%). Eighty-seven percent reported having an undilated eye check during a standard clinic visit, 73% of which had occurred within the last year.

There was a considerable percentage increase of those with DED (28%), and DME (42%), currently enrolled in a diabetes management support programme compared with 24% of patients without DED. Most respondents (84%) said that the programmes included education on the importance of screening for diabetic eye complications. Of note however, was that almost one in five (19%) respondents without DED did not have information on eye complications in the support programme (see Table 5.4).

Table 5.4: Diabetes management programmes

Support programmes	Without DED (n=2,998)	With DED (n=847)	With DME (n=332)
Enrolled in a programme	708 (23.6%)	235 (27.7%)	138 (41.6%)
Includes education on screening for diabetic eye complications	548 (80.7%)	200 (86.6%)	125 (93.3%)

NB [1]: The values (n=xx) show the maximum number of respondents in that group, but percentages are calculated from non-missing values for that group for the specific question.

Sixty-nine percent of patients thought that their diabetes was well controlled, while 28% said their condition was not controlled. When examining a potential relationship between diabetes control and DED, findings showed a 5.8% - 6.2% increase of those with DED (32%) and DME (33%) who reported that their diabetes was not controlled compared with those without DED (27%) (see Table 5.5)



Photo: Shabana Shahzad

Table 5.5: Self-reported diabetes control

Diabetes control	Without DED (n=2,855)	With DED (n=847)	With DME (n=332)
Very well	559 (19.6%)	146 (17.4%)	73 (22.1%)
Well	1,454 (50.9%)	413 (49.2%)	142 (43%)
Total controlled	2,013 (70.5%)	559 (66.6%)	215 (65.1%)
Not very well	645 (22.6%)	216 (25.7%)	91 (27.6%)
Not well at all	115 (4.0%)	56 (6.7%)	17 (5.2%)
Total not controlled	760 (26.6%)	272 (32.4%)	108 (32.8%)

NB [1]: The values [n=xx] show the maximum number of respondents in that group, but percentages are calculated from non-missing values for that group for the specific question.

Most patients understand that careful management of their diabetes, including glucose control, is critical for the prevention of complications, such as DED. Over half (59%) of those surveyed said that free or low-cost medicines or monitoring materials were an essential part of how they management their diabetes. Other critical areas were: support from family or friends (43%), health education and information (40%), and professional coordination of health care services amongst providers (27%) (see Table 5.6).

Table 5.6: Supporting services to improve diabetes management

Service	(n=3,909)
Free or low cost medicines or monitoring materials	2,299 (58.8%)
Support from family or friends	1,681 (43.0%)
Health education and information	1,563 (40.0%)
Coordination of healthcare and services by a professional	1,073 (27.4%)
Support groups	714 (18.3%)
Mobile services (services that travel to or near your home)	242 (6.2%)
Emergency helpline	232 (5.9%)
None	422 (10.8%)
Other	232 (5.9%)

Phase II: Quantitative Results

Health Care Professionals

Health care providers have an important role in helping people with diabetes, and their families, to better understand the impact and consequences of poor diabetes control through providing education about complications and the potential impact on their function, autonomy, and livelihood. Part of this role is to provide guidance on prevention strategies and improve the overall management of diabetes.

As such, a wide range of topics related to diabetes, and its management, were addressed by the health care professional during routine visits including: diabetes management and monitoring, eye care and exams, medicines, and nutrition (see Table 5.7).

Most primary care providers (65% - 95%) and diabetes specialists (79% - 94%) regularly discussed general management and monitoring of a person's diabetic condition and this included diet, nutrition, and foot care. This was not the case for the topic of eye care and eye exams where only 47% of primary care providers and 62% of diabetes specialists discussed potential complications routinely with patients. While it was gratifying to note that 94% of ophthalmologists routinely discussed eye complications the other diabetes related topics were less evident where around a third discussed topics such as: blood pressure, diet, and exercise.

Table 5.7: Health care topics discussed with patients during a routine visit

Topic	All Providers (n=1,707)	Primary care (n=268)	With DED (n=303)	With DME (n=678)
Diabetes management and monitoring	1,326 (77.7%)	253 (94.4%)	284 (93.7%)	410 (60.5%)
Diet/nutrition	1,083 (63.4%)	237 (88.4%)	278 (91.7%)	241 (35.5%)
Exercise/physical activity	1,042 (61.0%)	232 (86.6%)	266 (87.8%)	222 (32.7%)
Medicines	1,210 (70.9%)	254 (94.8%)	288 (95.0%)	310 (45.7%)
Foot care and inspection	701 (41.1%)	175 (65.3%)	239 (78.9%)	50 (7.4%)
Blood pressure	1,071 (62.7%)	244 (91.0%)	280 (92.4%)	244 (36.0%)
Eye care and exams	1,249 (73.2%)	127 (47.4%)	189 (62.4%)	634 (93.5%)
Lipid check	835 (48.9%)	214 (79.9%)	253 (83.5%)	151 (22.3%)
Other	13 (0.8%)	1 (0.4%)	7 (2.3%)	1 (0.1%)
None of the above	31 (1.8%)	4 (1.5%)	2 (0.7%)	13 (1.9%)

Over half (59%) of all providers either did not have any information on diabetes and potential eye complications (29%) or that which was on eye complications was either insufficient (22%) or was not included (8%). As health education was identified as an important tool for patients, it is concerning that only 34% of all providers reported to have sufficient information about diabetes and potential eye complications available to their patients.

The nature and availability of information also varied by type of provider: 22% of the primary care providers and 37% of ophthalmologists, had material that they deemed to contain sufficient information on eye complications. It is concerning that over half (53%) of the

ophthalmologists, either had insufficient information on eye complications (15%) or did not have any written information, on either diabetes or its eye-related complications, available for their patients (38%).

A lack of available information and guidance for patients is only one part of the story as it relates to the sound management of a person's diabetic condition. The study underlined a serious deficit in available written protocols and guidelines for providers.

Substantially less than half (44%) of all providers had written protocols for the detection and management of diabetes-related vision issues available and being used by staff. Of concern is that finding that 44% of providers either did not have access to protocols (35%) or the protocols were not used by staff (9.3%).

Across all types of providers, the lack of, or non-application of, protocols or guidelines was substantial. Fifty-three percent of primary care providers reported either no written protocols (41%) or those available were not used by staff (13%). Furthermore, the finding that specialists in disease-specific fields (44% diabetes specialist and 33% of ophthalmologists) did not have protocols available is a worrying gap in the health care system and professional education (see Table 5.8).

Table 5.8: Availability and use of protocols

Response	All Providers (n=1,687)	Primary care (n=264)	Diabetes Specialist (n=298)	Ophthalmologist (n=672)
Yes, available and used by staff	743 (44%)	94 (35.6%)	115 (38.6%)	328 (48.8%)
Yes, available but not used by staff	157 (9.3%)	34 (12.9%)	34 (11.4%)	66 (9.8%)
Not available	596 (35.3%)	107 (40.5%)	131 (44.0%)	222 (33.0%)
Don't know/not sure	191 (11.3%)	29 (11.0%)	18 (6.0%)	56 (8.3%)

The level of relevant experience and training on DED, including DME, of ophthalmologists was varied with one in five (21%) reporting no specific training on the diagnosis or treatment of DR and / or clinically significant DME.

Of those who had received training, 55% had received the training within the past year, while 18% received their training five years ago or longer. About three-quarters (77%) of ophthalmologists would be interested in further education and certification on DME, angiogenesis and anti-VEGF therapies.

Nature and Information about Complications

There was a relatively high level of awareness among patients of the most common complications arising from diabetes, with the most well-known being vision loss (85%). While this finding is positive on the one hand, between 25% - 33% of respondents were in fact not aware that amputation, neuropathy, kidney disease, foot ulcers and cardiovascular disease or stroke were potential complications of diabetes (see Table 5.9).

Phase II: Quantitative Results



Table 5.9: Awareness of diabetes complications

Complications (or problems)	(n=3,966)
Vision loss	3,385 (85.4%)
Amputation	2,993 (75.5%)
Loss of feeling in hands or toes (neuropathy)	2,850 (71.9%)
Kidney disease	2,817 (71.0%)
Foot ulcers	2,722 (68.6%)
Cardiovascular disease/Stroke	2,656 (67.0%)
None	115 (2.9%)
Other	373 (9.4%)
Don't know/Not sure	103 (2.6%)

The study was able to help discern the tangible differences between being aware of complications and being concerned about the complications from a personal perspective. The finding that compared with all other complications (cardiovascular disease, amputation, kidney disease, neuropathy, and foot ulcers) vision loss was the patients' greatest concern by more than a factor of two. Awareness and concern do not necessarily translate into knowledge and action; therefore, these findings stress the need for targeted and substantive patient education on preventative strategies for the onset of diabetes-related eye complications (see Table 5.10).

Table 5.10: Concerns about diabetes complications

Complications	(n=3,934)
Vision loss	1,568 (39.9%)
Cardiovascular disease / stroke	654 (16.6%)
Amputation	619 (15.7%)
Kidney disease	513 (13.0%)
Loss of feeling in hands or toes (neuropathy)	143 (3.6%)
Foot ulcers	68 (1.7%)
None	130 (3.3%)
Other	26 (0.7%)
Don't know/Not sure	137 (3.5%)

Fifty-eight percent of adults with diabetes reported that they had at least one complication associated with diabetes. One in every four (26%) of those surveyed had vision loss, as a result of DED or DME, 21% reported the evidence of neuropathy, cardiovascular disease or stroke (13%), and kidney disease (11%) (see Table 5.11).

More than one in three patients (35%) with DED and DEM had neuropathy, which was more than twice those without DED (15%). Similarly, there was a 13% increase of those with DED, and DME, who had kidney disease compared with those without DED. Across all complications, there was consistently marked percentage increase for those with DED and DME versus those without DED.

Table 5.11: Presence of diabetes complications without DED, with DED or DME

Complication	All respondents (n=3,803)	Without DED (n=2,676)	With DED (n=811)	With DME (n=316)
Any complication	2,200 (57.8%)	1,230 (46.0%)	680 (83.8%)	290 (91.8%)
Vision loss	970 (25.5%)	378 (14.1%)	401 (49.4%)	191 (60.4%)
Loss of feeling in hands or toes (neuropathy)	794 (20.9%)	402 (15.0%)	281 (34.6%)	111 (35.1%)
Cardiovascular disease / stroke	497 (13.1%)	275 (10.3%)	167 (20.6%)	55 (17.4%)
Kidney disease	434 (11.4%)	207 (7.7%)	163 (20.1%)	64 (20.3%)
Foot ulcers	186 (4.9%)	102 (3.8%)	57 (7.0%)	27 (8.5%)
Amputation	131 (3.4%)	63 (2.4%)	38 (4.7%)	30 (9.5%)
Other	173 (4.5%)	85 (3.2%)	72 (8.9%)	16 (5.1%)
None	1,603 (42.2%)	1,446 (54.0%)	131 (16.2%)	26 (8.2%)

NB [1]: The group of patients with DED excludes patients with DME.

NB [2]: Any complications is 100%-none, excluding their DED or DME diagnosis.

Screening for Diabetic Eye Disease

Adults with Diabetes

Forty-three percent of respondents had regular discussions, regarding the possibility of eye complications, with their doctor either every visit, or multiple times per year. However more than a quarter (27%) had either never discussed eye complications (12%) or did so only after the onset of symptoms (16%). For only 26% of the respondents, these discussions were on an annual basis (see Table 5.12).

Table 5.12: Frequency of discussions with health care professionals about eye complications

How often do you discuss the possibility of eye complications with your health care professional?	(n=3,919)
Every visit	933 (23.8%)
Multiple times per year	732 (18.7%)
Once per year	1,030 (26.3%)
Only when symptoms arise	607 (15.5%)
Never	451 (11.5%)
Don't know/Not sure	166 (4.2%)
None	130 (3.3%)
Other	26 (0.7%)
Don't know/Not sure	137 (3.5%)

Phase II: Quantitative Results

While the study showed that 75% of those surveyed said they do what they can to prevent vision problems, such as regular screenings and visits to specialists, it was also evident that there are both myths and misperceptions about eye health. One in five (22%) respondents thought that vision problems were a normal part of ageing and 14% did not make any special efforts to prevent vision problems.

Seventy-nine percent of respondent have had an eye exam for DED, and for 77% of those it was within the last year and a 17% had an exam more than one year ago but less than two. Notwithstanding the relatively high rate of eye exams, there remains the one in five patients (21%) who have never had an exam (see Table 5.13).

Awareness of a national government-sponsored screening programme was relatively low (29%) however, the existence of such programmes is likely to vary considerably between countries.

Table 5.13: Eye exams for DED

Question	Response	(n=3,893)
Have you ever had an eye exam for diabetic eye disease?	Yes	3,078 (79.1%)
	No	815 (20.9%)
How long ago was your last eye exam?	Within the last year	2,354 (77.3%)
	More than 1 year ago but less than 2 years	501 (16.5%)
	More than 2 years ago but less than 3 years	104 (3.4%)
	More than 3 years ago but less than 5 years	40 (1.3%)
	Five or more years ago	37 (1.2%)
	Don't know/Not sure	9 (0.3%)

NB [1]: The values [n=xx] show the maximum number of respondents in that group, but percentages are calculated from non-missing values for that group for the specific question

Health Care Professionals

Seventy-three percent of all providers screened patients for DED, 79% predominantly in a clinic, but 15% also did so via outreach which included mobile clinics.

In general, eye exams were more commonly performed by ophthalmologists who relied on a range of procedures: 89% use optical coherence tomography, 99% funduscopy, and 86% use fluorescein angiography.

In some cases, certain eye exams were also performed in the practice of the primary care providers and diabetes specialists. Funduscopies were performed within 42% of primary care and 58% of diabetes specialists' practices whilst fluorescein angiographies were performed in 15% and 27% respective practices.

Timing for initial eye exams for adults with diabetes varied depending upon whether the diagnosis was type 1 or type 2 diabetes.

For people with type 1 diabetes, 51% of the providers recommended an initial eye exam as soon as the patient was diagnosed, 21% after a pre-determined number of years, and 14% said the timing varied on a case by case basis. This approach was generally consistent across the various provider groups.

For people with type 2 diabetes, over three-quarters (77%) of the providers recommended an initial eye exam as soon as the patient was diagnosed.

Although relatively small in number, it is disquieting that some 4% of providers only recommend screening once symptoms occur regardless of type of diabetes (see Table 5.14 and 5.15).

Table 5.14: Recommended timing of the initial eye exam for adults with type 1 diabetes

Response	All respondents (n=1,627)	Primary care (n=255)	Diabetes specialist (n=283)	Ophthalmologist (n=649)
As soon as they are diagnosed	827 (50.8%)	139 (54.5%)	132 (46.6%)	343 (52.9%)
After a predetermined number of years	345 (21.2%)	48 (18.8%)	99 (35.0%)	144 (22.2%)
No standard practice, timing varies case by case	222 (13.6%)	38 (14.9%)	26 (9.2%)	85 (13.1%)
When a patient reports eye/vision problems	66 (4.1%)	14 (5.5%)	12 (4.2%)	15 (2.3%)
After a predetermined age	53 (3.3%)	2 (0.8%)	6 (2.1%)	28 (4.3%)
Other	38 (2.3%)	5 (2.0%)	6 (2.1%)	13 (2.0%)
Don't know/Not sure	76 (4.7%)	9 (3.5%)	2 (0.7%)	21 (3.2%)

Table 5.15: Recommended timing of the initial eye exam for adults with type 2 diabetes

Response	All respondents (n=1,655)	Primary care (n=257)	Diabetes specialist (n=297)	Ophthalmologist (n=659)
As soon as they are diagnosed	1,274 (77.0%)	182 (70.8%)	257 (86.5%)	530 (80.4%)
No standard practice, timing varies case by case	177 (10.7%)	38 (14.8%)	17 (5.7%)	66 (10.0%)
When a patient reports eye/vision problems	60 (3.6%)	13 (5.1%)	8 (2.7%)	17 (2.6%)
After a predetermined number of years	50 (3.0%)	12 (4.7%)	9 (3.0%)	22 (3.3%)
After a predetermined age	10 (0.6%)	2 (0.8%)	0 (0.0%)	4 (0.6%)
Other	31 (1.9%)	5 (1.9%)	4 (1.3%)	9 (1.4%)
Don't know/Not sure	53 (3.2%)	5 (1.9%)	2 (0.7%)	11 (1.7%)

Phase II: Quantitative Results

The protocol for the timing of follow-up eye examinations for people with diabetes was once per year for 76% of providers. However, the timing did vary amongst providers with only 69% of primary care providers recommending yearly follow-up exams compared with 86% of diabetes specialists.

Sixty percent of providers reported a wait time of less than one month to schedule an appointment, but 18% reported a waiting time of between one and three months. Waiting times did, however, vary considerably across provider groups. Fifty-three percent of primary care providers reported a waiting time of less than one week, compared with only 20% of ophthalmologists.



Significantly two-thirds (65%) of the ophthalmologists reported that most of their patients presented for screening when visual problems had already occurred. A further 6.2% sadly said it was already too late for effective treatment when most of their patients presented for a consult. For some 29% of ophthalmologists patients presented in time for the screening.

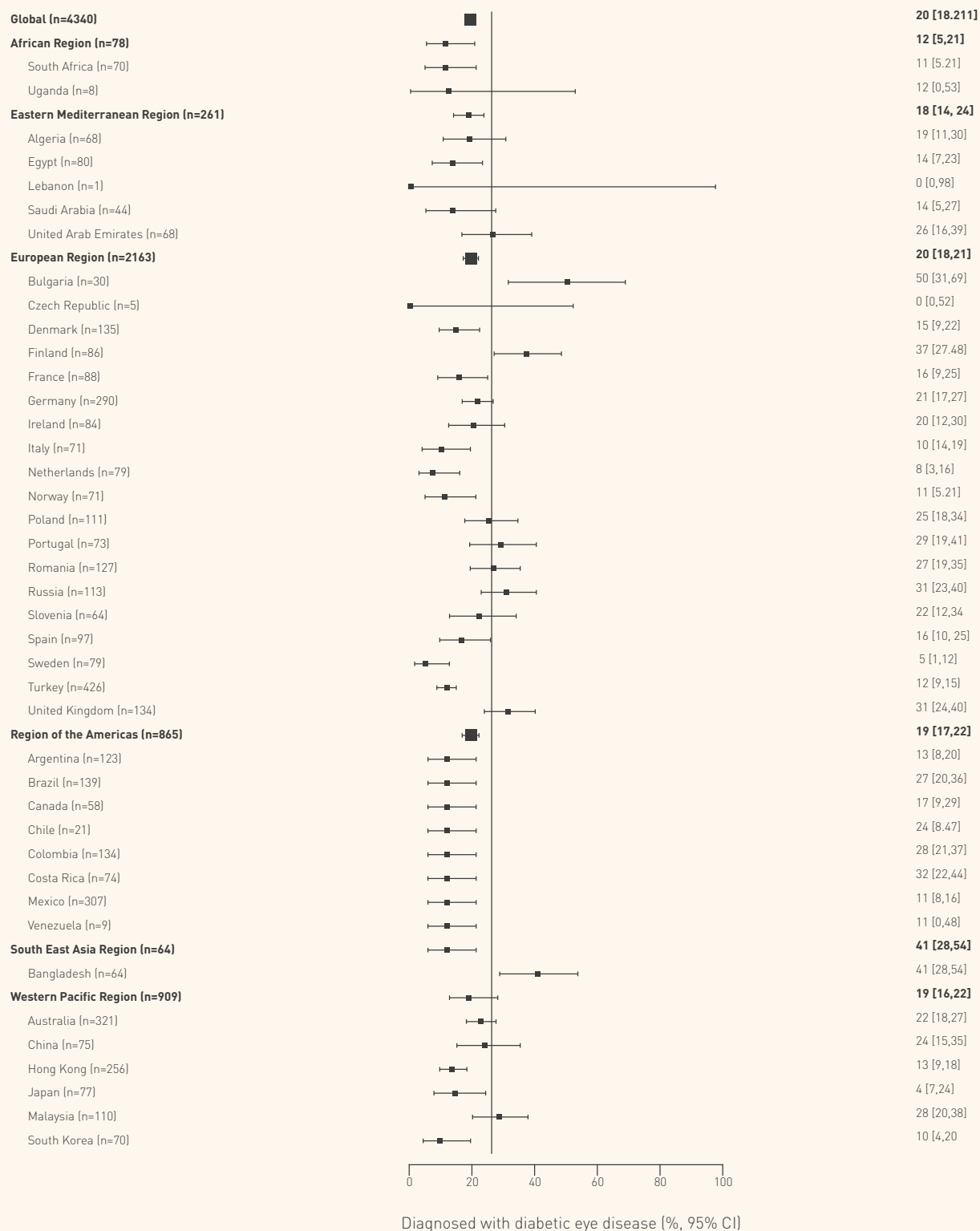
Diabetic Eye Disease and Diabetic Macular Edema

Globally, 20% of adults with diabetes, surveyed across 41 countries, were diagnosed with DED: the South-East Asia region (41%), the European region (20%), the Region of the Americas (19%), the Western Pacific region (19%), the Eastern Mediterranean region (18%), and the Africa region (12%)(see Figure 5.3).

Globally, 7.6% of patients surveyed had been diagnosed with DME. Rates of DME for the Region of the Americas were 6.4%, the South-East Asia region (6.3%), and the Western Pacific region (5.6%), whereas the European and Eastern Mediterranean region were slightly higher at 8.9% and 11%, respectively (see Figure 5.4).

Whilst these estimates might be interpreted as suggesting a considerable global variation in the proportion of DED and DME, it should be noted that respondents were self-selected predominantly from patient support organizations and as a result, this study population is not representative of the broader population of people living with diabetes and DED. In addition, there are likely to be differences in key risk factors, such as age and time since diagnosis, which explain in part the variance.

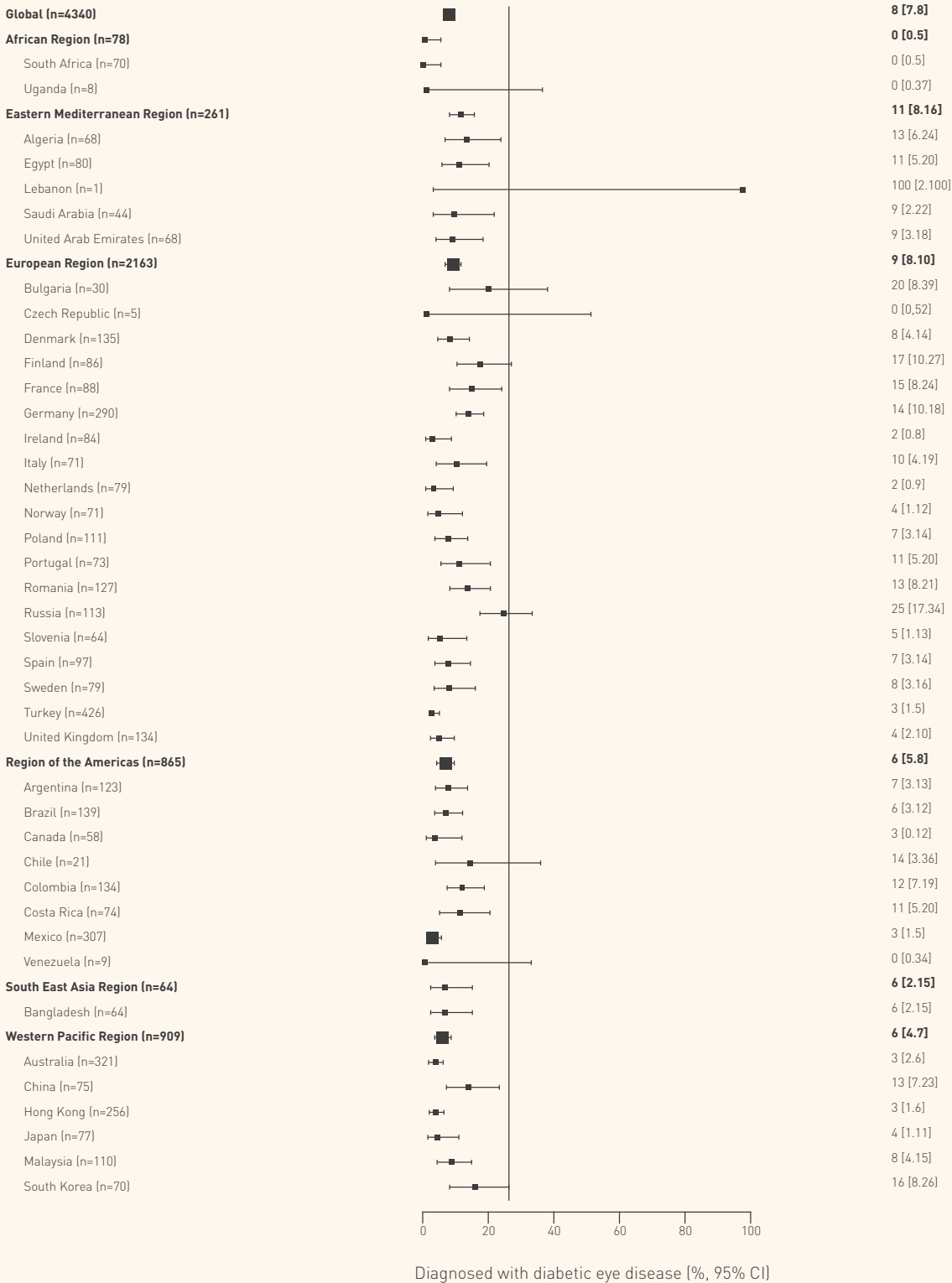
Figure 5.3: Frequency of adults with diabetes diagnosed with DED



NB [1]: This excludes people diagnosed with DME. The numbers in parentheses on the left are the total number of respondents. The actual values for the frequency of diabetic eye disease and the 95% confidence intervals are given on the right hand side of the graph. The confidence intervals are based on the Clopper-Pearson method for the binomial distribution

Phase II: Quantitative Results

Figure 5.4: Frequency of adults with diabetes diagnosed with DME



NB [1]: The numbers in parentheses on the left are the total number of respondents. The actual values for the frequency of diabetic macular edema and the 95% confidence intervals are given on the right hand side of the graph. The confidence intervals are based on the Clopper-Pearson method for the binomial distribution.



Potential Factors Contributing to the Onset of Diabetic Eye Disease

The proportion of DED (Figure 5.5 (A)) and DME (Figure 5.5 (B)) varied by age group, type of diabetes, and time since diagnosis. The proportion of those surveyed with DED and DME varied by age, of those aged between 18-39 years of age, 18% had DED and 6.8% had DME. This increased to 19% for DED but remained at 6.5% for DME in the 40-59 year age group, and increased to 21% for DED and 9.1% for DME in the 60-79 year age group. In people 80 years of age or older, the proportion of DED remained at 21% but increased to 15% for DME.

There was a strong association between the proportion of people with DED or DME and the time since diagnosis of diabetes. For those within their first year of diagnosis, 11% had DED and 4.6% had DME. There was a varied yet notable percentage increase of DED and DME in those respondents diagnosed between one and ten years ago, (1-5 years (DED 8.7%, DME 5.5%) and 6-10 years (DED 13%, DME 5.3%)). Thereafter, marked rises were evident for people diagnosed 11-15 years with 19% having DED and 7% DME, a percentage which increased further 21 years or more post diagnosis, 40% with DED and 14% DME.

The decrease in the proportion of people with DED diagnosed within the past year compared with those within the past one to five years is likely due to those with type 2 diabetes, which due to its nature may have remained undiagnosed for several years prior.

For those respondents who felt their diabetes was controlled, 20% had DED and 7.7% had DME, compared with those who reported poor control there was only a slight increase noted, with 24% reporting DED and 9.5% with DME.

DED was more frequent in respondents with type 1 (25%) versus type 2 (16%) diabetes whereas there was little variation in reported DME for those with type 1 (8.1%) and type 2 (7.7%) diabetes.

Phase II: Quantitative Results

Figure 5.5: Factors that could influence the onset of DED (A)

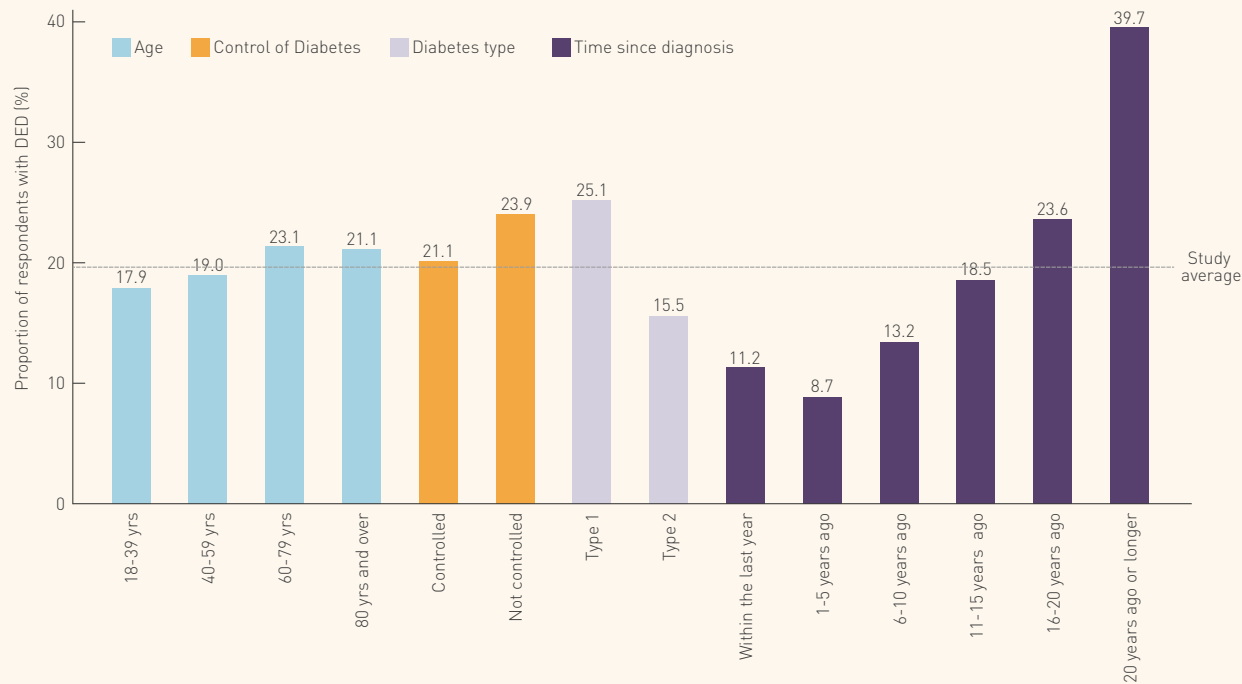
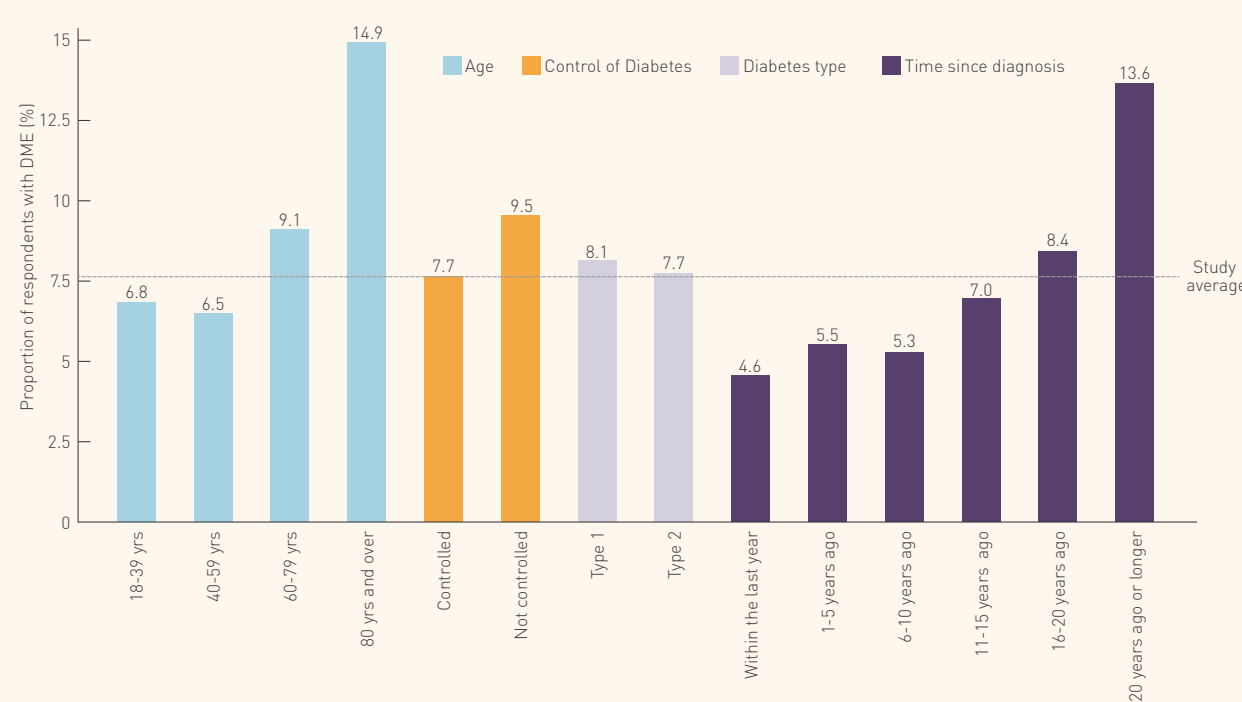


Figure 5.5: Factors that could influence the onset of DME (B)



Treatment of Diabetic Eye Disease and Diabetic Macular Edema

Treatment was assessed separately in patients with DED and those with DME. Overall, 62% of respondents diagnosed with DED received some form of treatment with the most common treatment being laser (74%), followed by surgery (29%), and anti-VEGF therapy (24%) (see Table 5.16).

Ninety-one percent of those with DED either had completed, or were still undergoing treatment. Over three-quarters (78%) felt that the treatment had been successful and either their vision had improved (45%) or their vision had stayed the same (33%). A third of people with DED had not received treatment, the most common reason cited was that their doctor had not recommended any treatment.

In patients with DME, 85% received treatment, including laser (82%), anti-VEGF therapy (49%), and surgery (33%). Ninety-one percent had completed or were still undergoing treatment and the majority (81%) felt that the treatment was successful, including 46% who said that their vision had improved. In those who had not received treatment (11%), almost one-third said that their doctor did not recommend treatment whilst others stated a variety of reasons, including: still waiting for treatment (26%), the treatment was too expensive (16%), and the treatment would not be effective (13%).

A small number of respondents started but did not complete recommended treatment for DED (6.4%) or DME (7.1%). For those with DED, who did not complete treatment, the most common reasons were: the treatment was not effective (17%), the eye doctor was located too far away (17%), and there was a general fear of the treatment (17%). Forty-four percent of those with DME, who did not complete treatment, cited the cost of the treatment as a barrier, 38% said that the treatment was not effective, and for some the appointment times were inconvenient (31%).

The majority (87%) of those with DME would prefer a proactive treatment to prevent further vision loss rather than reactive treatment once further vision loss had occurred.

Phase II: Quantitative Results

Table 5.16: Treatment characteristics of patients with DED and DME

Question	Response	With DED (n=842)	With DME (n=282)
Have you had any treatment for diabetic eye disease?	Yes	519 (61.6%)	239 (84.8%)
	No	282 (33.5%)	32 (11.3%)
	Don't know/Not sure	41 (4.9%)	11 (3.9%)
What treatment did you receive?	Laser	374 (73.5%)	195 (82.3%)
	Anti-VEGF therapy	121 (23.8%)	116 (48.9%)
	Surgery	148 (29.1%)	77 (32.5%)
	Other	73 (14.3%)	16 (6.8%)
Did you complete the treatment?	Yes	312 (60.6%)	129 (54.0%)
	No	33 (6.4%)	17 (7.1%)
	Still receiving treatment	154 (29.9%)	89 (37.2%)
	Don't know / Not sure	16 (3.1%)	4 (1.7%)
Do you feel that the treatment worked?	Yes, and vision improved	214 (45.1%)	102 (46.2%)
	Yes, but vision stayed the same	156 (32.9%)	77 (34.8%)
	No	40 (8.4%)	14 (6.3%)
	Still waiting to know	38 (8.0%)	20 (9.0%)
	Don't know/Not sure	26 (5.5%)	8 (3.6%)
What is/are the reason(s) that you did not complete the treatment?	Did not like the treatment	3 (10.0%)	2 (12.5%)
	Treatment was not effective	5 (16.7%)	6 (37.5%)
	Treatment was too expensive	4 (13.3%)	7 (43.8%)
	Eye doctor was located too far away	5 (16.7%)	3 (18.8%)
	Appointment times were not convenient	3 (10.0%)	5 (31.3%)
	Too much burden on my family/friends	3 (10.0%)	1 (6.3%)
	I was too busy	2 (6.7%)	1 (6.3%)
	I was fearful (scared) of treatment	5 (16.7%)	2 (12.5%)
	Other	18 (60.0%)	2 (12.5%)
What are the reason(s) that you have not had treatment for diabetic eye disease?	My doctor did not recommend any treatment	193 (72.3%)	10 (32.3%)
	Treatment would not be effective	11 (4.1%)	4 (12.9%)
	Treatment is not accessible	10 (3.7%)	3 (9.7%)
	Still waiting for treatment	28 (10.5%)	8 (25.8%)
	Treatment is not important to me	1 (0.4%)	1 (3.2%)
	Too expensive	18 (6.7%)	5 (16.1%)
	No insurance	9 (3.4%)	1 (3.2%)
	I'm too busy	5 (1.9%)	1 (3.2%)
	I'm fearful of treatment	7 (2.6%)	1 (3.2%)
	Other	34 (12.7%)	4 (12.9%)

NB [1]: The values [n=xx] show the maximum number of respondents in that group, but percentages are calculated from non-missing values for that group for the specific question.

NB [2]: Respondents could select multiple answers so the percentages do not add to 100%.

Multiple treatments were available in the practices of ophthalmologists namely: laser photocoagulation was offered in 80% of practices, anti-VEGF therapies (77%), intravitreal steroid injections (74%), uncomplicated vitrectomy (64%), and complex vitreo-retinal surgery (61%). Eighty-four percent of ophthalmologists personally administered treatment for DR.

More than half of the ophthalmologists reported that diabetes duration, high glucose levels, and the presence of co-morbidities influenced their treatment decisions for patients diagnosed with DR and DME. The patient's ability to adhere to recommendations (49%) and the age of a patient (44%) were also stated as significant influences (see Table 5.17).

Table 5.17: Patient characteristics that influence treatment decisions

Factor	Ophthalmologist (n=480)
High glucose levels	302 (62.9%)
Presence of comorbidities such as hypertension, etc.	297 (61.9%)
Diabetes duration	284 (59.2%)
Patient adherence to recommendations	235 (49.0%)
Patient's age	210 (43.8%)
Patient educational level	128 (26.7%)
Ability or inability to pay	104 (21.7%)
Insurance restrictions	87 (18.1%)
Patient's gender	29 (6.0%)
None of the above	58 (12.1%)
Not applicable	8 (1.7%)

Impact of Diabetic Eye Disease and Diabetic Macular Edema

More than three quarters (79%) of patients with DED or DME said that their vision was impaired, either slightly (50%) or significantly (29%).

For those with DED, vision loss and impairment had a significant impact on the autonomy of respondents as well as their lifestyle choices. As examples, 36% had difficulties driving a car, working or keeping a job (27%), and completing basic household responsibilities, such as cooking or cleaning (23%) (see Table 5.18).

Furthermore, respondents with DED said that vision loss resulted in a restricted social life in the following ways: the ability to travel (27%), undertaking leisure activities and exercise (27%), and 19% struggled to interact with friends and family. One in five (20%) reported that changes in vision made it difficult to manage their underlying diabetes.

The impact on people with DME was even more severe as 85% reported that vision loss led to difficulty with at least one daily activity. Almost half (47%) of those with DME had struggled with driving a car whilst 30% had concerns about keeping a job or completing basic household activities.

Phase II: Quantitative Results

Table 5.18: Activities affected through vision impairment and loss

Vision issue	With DED (n=600)	With DME (n=254)
Driving (a car/vehicle)	218 (36.3 %)	119 (46.9%)
Travelling	162 (27.0%)	78 (30.7%)
Work or keeping a job	160 (26.7%)	74 (29.1%)
Leisure activities/exercise	159 (26.5%)	74 (29.1%)
Household responsibilities, such as cooking or cleaning	135 (22.5%)	75 (29.5%)
Managing my diabetes	120 (20.0%)	51 (20.1%)
Social interactions with family/friends	112 (18.7%)	54 (21.3%)
Other	62 (10.3%)	30 (11.8%)
None	124 (20.7%)	38 (15.0%)

Impact on Employment Status

For many patients with DED and corresponding vision loss, the reported difficulty with maintaining paid employment may have serious consequences for, not only the individual, but also quite often the extended family. Compared with 48% of people without DED, 41% of those with DED and 39% with DME were currently employed in a salaried post. Eighteen percent of those with DED did not work compared with 13% of those without DED.

The proportion of people working without pay or volunteering was similar for those with and without DED (DED 8.7% without DED 7.7%) and slightly higher for those with DME (12%).

Table 5.19: Socio-economic profile of patients without DED, with DED or DME

Are you currently working?	All respondents (n=3,748)	Without DED (n=2,610)	With DED (n=817)	With DME (n=321)
Working for pay	1,721 (45.9%)	1,262 (48.4%)	333 (40.8%)	126 (39.3%)
Working without pay at home (e.g. housework, farming)	227 (6.1%)	151 (5.8%)	50 (6.1%)	26 (8.1%)
Volunteering	82 (2.2%)	49		
[1.9%]	21 (2.6%)	12 (3.7%)		
Retired	1,061 (28.3%)	694 (26.6%)	252 (30.8%)	115 (35.8%)
Student	140 (3.7%)	120 (4.6%)	16 (2.0%)	4 (1.2%)
Not working	517 (13.8%)	334		
[12.8%]	145 (17.7%)	38 (11.8%)		

Sixty-six percent of people without DED aged between 18 and 39 years old were in paid employment, and similarly for those in the 40 to 59 year age group (64%) (see Figure 5.6).

Whilst seventy-four percent of those in the 18-39 year age group with DED were in paid employment, this proportion decreased significantly to 52% in the 40-59 age group and then to 8.7% in those aged between 60-79 years. Similarly, in people with DME, more than 70% of those in 18-39 year age group were in paid employment, and this decreased to 61% for people aged between 40-59 years to 7.9% for those aged 60-79 years.



Phase II: Quantitative Results

Figure 5.6. Employment status



Reliance on Government Assistance

About two-thirds of all respondents (63%) did not receive any form of government. However where assistance was used, the most common type was medical (20%) and pension (14%) assistance. While small in numbers, respondents who received government assistance increased in those with DED (44%) and DME (50%) compared to those without DED (33%). In particular, there was a significant increase in both income and food assistance (see Table 5.20).

Table 5.20: Respondents receiving government assistance

Do you receive assistance from the government?	All respondents (n=3,639)	Without DED (n=2,549)	With DED (n=786)	With DME (n=304)
Income assistance	350 (9.6%)	195 (7.7%)	96 (12.2%)	59 (19.4%)
Medical assistance	724 (19.9%)	467 (18.3%)	185 (23.5%)	72 (23.7%)
Food assistance	74 (2.0%)	29 (1.1%)	21 (2.7%)	24 (7.9%)
Housing assistance	116 (3.2%)	69 (2.7%)	30 (3.8%)	17 (5.6%)
Pension assistance	513 (14.1%)	307 (12.0%)	153 (19.5%)	53 (17.4%)
None of the above	2,299 (63.2%)	1,708 (67.0%)	439 (55.9%)	152 (50.0%)
Not working	517 (13.8%)	334		
(12.8%)	145 (17.7%)	38 (11.8%)		

While the study showed an association between increasing age and the need for assistance, overall it was most evident in the subpopulation of respondents with DME (see Figure 5.7).

For those in the youngest age group (18-39 years), 47% with DME received some form of assistance compared with 34% with DED and 26% without DED. At the peak of one's normal working life (40-59 years) almost half (49%) of those with DME received assistance versus 41% with DED and 29% without DED.

The percentage difference between the groups was not as significant in the 60-79 years and 80 years and older yet there was an overall greater dependence on the government regardless of whether the patient had DED, or not, with between 42% and 55% receiving services.

Phase II: Quantitative Results

Figure 5.7. Reliance on government assistance



Within the past year, 20% of people without DED reported trouble paying for food at some time, compared with 23% for people living with DED and to 26% of people living with DME (see Table 5.21).

The study showed an association between the ability to pay for food and age, with higher frequency of people in the younger age groups having difficulty paying for food at any time within the previous year. In people between 18 and 39 years of age, 28% of those without DED, 30% with DED, and 43% with DME had trouble paying for food. For those in the 40 to 59 year age group, 20% of those without DED, 22% with DED, and 27% with DME struggled, and in the 60 to 79 year age group, 13% of those without DED, 20% with DED, and 17% with DME also had trouble paying for food at any time within the past year.

Table 5.21: Difficulties paying for food at any time within the past year

Group	Response	Without DED (n=2,595)	With DED (n=804)	With DME (n=320)
All Ages	Yes	512 (19.7%)	185 (23.0%)	83 (25.9%)
	No	2,083 (80.3%)	619 (77.0%)	237 (74.1%)
18-39 years	Yes	191 (28.1%)	60 (30.2%)	33 (43.4%)
	No	488 (71.9%)	139 (69.8%)	43 (56.6%)
	Total missing	182	6	2
40-59 years	Yes	208 (20.4%)	66 (22.1%)	27 (27.0%)
	No	814 (79.6%)	233 (77.9%)	73 (73.0%)
	Total missing	220	18	8
60-79 years	Yes	107 (12.7%)	57 (20.1%)	21 (16.5%)
	No	734 (87.3%)	226 (79.9%)	106 (83.5%)
	Total missing	144	18	2
80+ years	Yes	6 (11.3%)	2 (8.7%)	2 (11.8%)
	No	47 (88.7%)	21 (91.3%)	15 (88.2%)
	Total missing	20	1	0

Table 5.22: Self-reported healthy days of patients without DED, with DED or DME

Health Status	Without DED (n=3,161)	With DED (n=847)	With DME (n=332)
Self-rated health: Good	1,358 (54.0%)	341 (43.2%)	121 (38.9%)
Self-rated health: Fair/Poor	1,157 (46.0%)	448 (56.8%)	190 (61.1%)
Physically unhealthy days	933 (46.0%)	338 (54.5%)	149 (58.4%)
Mentally unhealthy days	847 (41.2%)	264 (43.9%)	117 (45.9%)
Unhealthy days	1,232 (61.1%)	406 (66.9%)	172 (68.8%)
Activity limitation days	620 (44.3%)	232 (51.1%)	103 (54.8%)

NB [1]: The group of respondents without diabetic eye disease in this table is all respondents minus those who stated that they have diabetic eye disease (i.e. includes those who were unsure and also includes those missing information about diabetic eye disease).

NB [2]: The values [n=xx] show the maximum number of respondents in that group, but percentages are calculated from non-missing values for that group for the specific question.

Phase II: Quantitative Results

Vision impairment, and associated vision loss, due to DED and DME, affected a person's ability to perform daily activities. The study showed that 64% of people with DME, and 58% of people with DED, experienced limitations in their daily activities compared to 37% of respondents who did not have DED.

Various health problems impacted daily activities, namely back or neck problems, hypertension, eye or vision problems, walking problems, mental or emotional health and arthritis. Respondents with DED and DME reported a higher proportion for particular conditions and impairments, such as eye or vision problems, heart, stroke and hypertension issues (see Table 5.23).

Table 5.23: Self-reported impairment or health problem resulting in limitations of daily activities

Limitations	Without DED (n=3,161)	With DED (n=847)	With DME (n=332)
Limited in any way in any activities because of an impairment or health problem	883 (37.1%)	440 (58.4%)	199 (64.2%)
Impairment or health problem			
Diabetes	763 (82.5%)	372 (84.9%)	158 (87.8%)
Back or neck problem	467 (59.3%)	195 (52.4%)	92 (57.1%)
Hypertension/high blood pressure	369 (48.9%)	202 (53.7%)	99 (62.3%)
Walking problem	368 (48.8%)	225 (59.4%)	87 (53.7%)
Eye/vision problem	300 (40.4%)	289 (71.9%)	145 (80.6%)
Mental or emotional health	298 (39.0%)	136 (37.5%)	56 (35.4%)
Arthritis/rheumatism	280 (38.1%)	153 (42.7%)	64 (41.8%)
Heart problem	176 (25.1%)	123 (33.4%)	53 (34.6%)
Fractures, bone/joint injury	166 (24.0%)	110 (31.4%)	45 (29.2%)
Lung/breathing problem	176 (24.9%)	84 (23.9%)	43 (27.9%)
Hearing problem	144 (20.9%)	83 (23.8%)	52 (34.0%)
Stroke problem	53 (7.9%)	38 (11.1%)	21 (14.2%)
Cancer	42 (6.2%)	17 (5.0%)	13 (8.7%)

NB [1]: The group of respondents without diabetic eye disease in this table is all respondents minus those who stated that they have diabetic eye disease (i.e. includes those who were unsure and also includes those missing information about diabetic eye disease).

NB [2]: The values [n=xx] show the maximum number of respondents in that group, but percentages are calculated from non-missing values for that group for the specific question

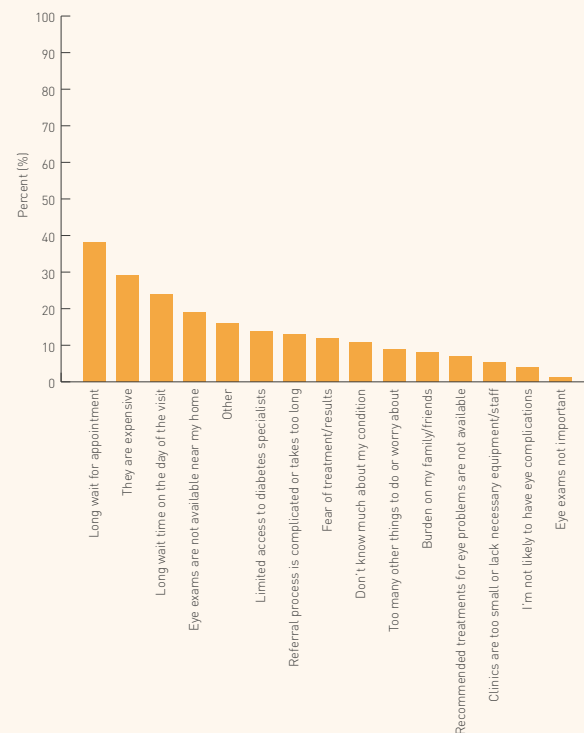
Barriers in the Care Pathway

An eye examination is a critical element in the prevention of eye complications and should be part of routine care for every person with diabetes. As such, it is vital to understand the personal and external barriers to obtaining an eye exam within the care pathway.

From the patient perspective, the greatest barriers cited related to health system constraints, primarily capacity and costs. Over a third of respondents (38%) cited the long wait times to schedule an appointment, as well as long wait times spent at the clinic on the day of the appointment (24%). Additionally, 29% of patients reported the cost of the eye examination was prohibitive. Nineteen percent also reported that facilities for eye examinations were not available near their place of residence and 13% said that the referral process was too complicated or took too long (see Figure 5.8).

The most significant barriers to optimizing eye health, reported by all providers, largely focused on patient responsibilities. From the provider perspective, the major barriers were: a patient's general lack of knowledge or awareness (43%), the patients feeling that eye exams were not important (33%), or that eye complications were unlikely (30%), and patients having a general fear of treatment or the test results (27%).

Figure 5.8: Barriers to eye examinations reported by adults with diabetes



Those challenges largely outside the control of patients, and primarily due to capacity and cost, included: the high cost of care (32%), long wait times to schedule an appointment (31%), limited access to eye specialists (27%), and the complicated or delayed referral process (26%) (see Table 5.24).

Phase II: Quantitative Results

Table 5.24: Major barriers to optimizing eye health as reported by health care professionals

Barrier	All providers (n=1,707)	Primary care (n=268)	With DED (n=303)	With DME (n=678)
Lack of knowledge and/or awareness	732 (42.9%)	99 (36.3%)	100 (33.0)	347 (51.2%)
Patients feel eye exams are not important	561 (32.9%)	79 (29.5%)	76 (25.1%)	243 (35.8%)
Cost of care	552 (32.3%)	73 (27.2%)	100 (33.0%)	255 (37.6%)
Long wait time for appointment	525 (30.8%)	117 (43.7%)	107 (35.3%)	186 (27.4%)
Patients feel eye complications are unlikely	510 (29.9%)	61 (22.8%)	70 (23.1%)	245 (36.1%)
Patients fear of treatment/results	467 (27.4%)	60 (22.4%)	77 (25.4%)	218 (32.2%)
Limited access to eye specialists	452 (26.5%)	102 (38.1%)	89 (29.4%)	148 (21.8%)
Referral process	446 (26.1%)	93 (34.7%)	64 (21.1%)	200 (29.5%)
Patients have competing responsibilities and priorities	389 (22.8%)	43 (16.0%)	61 (20.1%)	166 (24.5%)
Proximity to care	369 (21.6%)	58 (21.6%)	54 (17.8%)	167 (24.6%)
Limited access to diabetes specialists	332 (19.4%)	71 (26.5%)	31 (10.2%)	138 (20.4%)
Long wait time on the day of visit	272 (15.9%)	42 (15.7%)	53 (17.5%)	112 (16.5%)
Clinic too small or lack necessary equipment/staff	178 (10.4%)	37 (13.8%)	39 (12.9%)	56 (8.3%)
Patients they are a burden on family/friends	162 (9.5%)	24 (9.0%)	13 (4.3%)	79 (11.7%)
Recommended treatments are not available	148 (8.7%)	33 (12.3%)	31 (10.2%)	55 (8.1%)
Other	103 (6.0%)	16 (6.0%)	16 (5.3%)	31 (4.6%)

Ophthalmologists reported additional challenges and barriers to improving outcomes of patients once diagnosed with DED or DME. Two out of three ophthalmologists (66%) said that the greatest barrier was a late diagnosis.

The late diagnosis could be conceived as a by-product of a myriad of barriers cited by ophthalmologists including: the limited access to patient education on DED and DME (55%), poor multi-disciplinary team integration and communication (39%), complicated referral pathways (42%), reimbursement restrictions on approved therapy (36%), government or insurance not able to cover the patient's costs (31%), and ineffective screening services (28%). Notably, only 6.9% of ophthalmologists felt that the current therapies were not effective (see Table 5.25).

Table 5.25. Challenges for improving patient outcomes in DED

Challenge	Ophthalmologist (n=563)
Late diagnosis	373 (66.3%)
Limited access to patient education on diabetic retinopathy and diabetic macular edema	310 (55.1%)
Referral pathways	235 (41.7%)
Multi-disciplinary team integration is poor	220 (39.1%)
Reimbursement/restrictions on approved therapy	201 (35.7%)
Government/insurance not able to cover patient costs	176 (31.3%)
Ineffective screening services	157 (27.9%)
No universal guidelines on referral/screening	115 (20.4%)
No universal guidelines on how to treat	78 (13.9%)
No universal guideline on when to treat	68 (12.1%)
Current available therapies not effective	39 (6.9%)
Other	38 (6.7%)

As reported previously, long wait times to schedule an appointment and high cost of care were cited by both patients and providers as a key barrier to eye examinations and optimizing eye health.

Almost a third (32%) of ophthalmologists reported an average wait time for screening for DED of more than one month, 38% reported an average of more than one week but less than a month and only 22% reported less than one week wait time.

Not surprisingly, the wait times are driven by the limited capacity of providers to see patients. On average, ophthalmologists see almost 100 patients per week. Once screening has been performed, for the majority (59%) they provide diagnosis upon screening and in 19% of practice a diagnosis is provided within one week of screening. However, 5.1% of practices provide diagnosis within one to two months after screening.

Place of residence and proximity to care was also cited by 19% of patients and 25% of providers as barriers to eye examinations and care. The main practices were located in urban settings for 95% of ophthalmologists however, 17% of patients also lived in a non-urban setting. Only 12% of ophthalmologists perform screening via outreach, thereby making it difficult for people living in remote areas to access eye care services.



“The DR Barometer Study
has elicited unique insights
into the real-life experiences
of people living with DED
and health care professionals”

Summary

At a time of unpredictable global health challenges, two trends are prominent: a rapidly ageing global population and a burgeoning diabetes epidemic. For the first time in history, many people can expect to live into their 60s, 70s, 80s and beyond. Longevity represents significant advancements in nutrition, sanitisation, and medicine.

However, the social and economic consequences for individual health and wellbeing as well as already pressured health systems and national budgets are profound. Alongside the demographic upheaval of population ageing is the current reality that an estimated 415 million adults globally were living with diabetes in 2015, 75% of whom are in developing countries². By 2040, the number of adults with diabetes is set to rise to 642 million, constituting some 10% of the global adult population aged between 20 and 79 years².

Part of the immense healthcare challenge of increasing rates of diabetes worldwide is the myriad of clinical complications associated with living with the condition and its potential complications, such as diabetic eye disease (DED). DED includes diabetic retinopathy (DR), a preventable sight-threatening disease and a common complication of diabetes that accounts for 1% of all blindness and visual impairment in the world⁴⁴. It is a leading cause of vision loss among the working adult population^{44,45}. Often associated with DR, is diabetic macular edema (DME), which causes rapid central vision loss and may occur at any stage of the progression of DR.

DR in the early stage of development is often without symptoms, and for this reason regular eye screening of people with diabetes is crucial to ensure a prompt diagnosis and early treatment of retinopathy if required^{45,46}.

To address the complexities of optimising eye health in people living with diabetes around the globe, 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. Examining eye health in people with diabetes globally, and at a country-level in 41 countries, enables overall trends to be captured and assessed.

The DR Barometer Study has elicited unique insights into the real-life experiences of people living with DED and health care professionals. As such, it also provides new understandings of their experiences within the care pathway and barriers to overcome in order to improve ocular health outcomes.

Summary



Study Populations

Globally, 4,340 adults with diabetes and 2,329 health care professionals provided new information about the experiences of living with, managing and treating diabetes, DR and DME.

The study provides a snapshot of global diabetes-related eye health and its care in a self-selected population of adults with diabetes and health care professionals. It is notable that although the population of respondents completing the survey were self-selected, and therefore did not represent the wider global population, the observed proportion of people with diabetes reporting a diagnosis of DED or DME compared well with published data.

Globally, the patient survey ascertained combined DED and DME rates of 27% in adults with diabetes. This compared with published values of 35% for DR⁴⁷. Similarly, the patient survey derived global rates for DME of 7.6% as compared to 7.5% from published data⁴⁷.

Type 2 diabetes was the most prevalent amongst respondents and a little over a third of respondents were diagnosed with type 1 diabetes. A further 9.2% were unsure of their type of diabetes reflecting a concerning gap in the patient's understanding and health literacy in regards to their own diagnosis.

Just over half of the respondents were female, 26% were between 18 and 39 years of age, 38% were 40-59 years of age, 33% were 60-79 years of age, and the remaining 2.6% were 80 years of age or older.

Half of the respondents were diagnosed with diabetes more than 10 years ago, with almost a quarter 21 years ago or more. More than a quarter of people living with diabetes without DED reported that their condition was not well controlled and the proportion increased to a third of those with DED or DME.

Seventy-three percent of respondents had no reported evidence of DED or DME yet 20% had DED, and a further 7.6% DME.

A younger population was more likely to be associated with type 1 diabetes, which was the opposite of those with type 2 diabetes which tended to be an older population. This phenomenon is generally observed in the literature, with type 1 diabetes usually associated with early onset with genetic risk factors possibly playing a role in its progression². In contrast, type 2 diabetes is mostly associated with late onset, although the age of onset appears to be reducing worldwide², and can be influenced by factors affecting lifestyle including obesity, diet and exercise².

The DR Barometer Study found that the proportion of people with diabetes who reported a diagnosis of DED was higher in those with type 1 diabetes, in people with sub-optimally controlled diabetes, and in those with longer duration of diabetes and of older age. This is a finding consistent with the literature, where DR has been found to be more commonly associated with all such factors².

With respect to the prevalence of DED and DME within a regional setting, in the European region, 20% of respondents had DED and 8.9% had DME. In the Region of the Americas, the reported frequency of DED and DME was 19% and 6.4% respectively, and in the Western Pacific Region 19% had DED and 5.6% DME.

It is highly likely that the incidence of DED and DME both in this study and across countries is under-reported, as many people may not yet have been diagnosed because of the insidious nature of condition.

Fifty-eight percent of all adults with diabetes reported that they had at least one complication associated with their condition. Beyond DED or DME, one in five reported evidence of neuropathy, 13% with cardiovascular disease or stroke, and 11% reported having kidney disease.

Life changing complications were more likely to be experienced by those with DED and DME than those without DED. More than one in three had neuropathy, which was more than twice those without DED. Similarly, there was a 13% increase in kidney disease reported by respondents with DED and DME compared to those without DED. Across all complications, there was consistently marked percentage increase for those with DED and DME versus those without DED.

Awareness and Information for the Management of Diabetes and Diabetes-related Eye Complications

Evidence shows that the relationship between the patient and the health care professional is critical to optimal patient outcomes. Over half of the ophthalmologists said limited access to patient education on DR and DME was a serious challenge to improving patient outcomes in DED and DME. Patients also reported that education was one of the most important tools to improving their management of the condition yet almost a third did not receive any information on eye complications from traditional sources, such as their doctor or nurse.

Although people were most often informed about their diabetes by a doctor or nurse many respondents also valued diabetes, or other health organisations, and relied on information retrieved from the internet. People living with diabetes reported numerous challenges in managing their underlying condition, some that they had personal control over and others were external, best represented through inflexible or inadequate processes within health systems.

From the perspective of personal responsibility, the main issue related to diet, where almost half of respondents said it was too difficult to eat the right things. Other challenges included having competing priorities, not wanting to think about having diabetes, or simply not knowing enough about diabetes in general. It cannot be ignored that there were also external factors that signalled systemic barriers with around a quarter of respondents reporting the high cost of care and the long wait times to schedule an appointment with their specialist.

Summary

There was a considerable percentage increase of those with DME (42%) enrolled in a diabetes management support programme compared with 24% of patients without DED. Given the difficulty many had in controlling their diabetes, the low uptake of courses supporting sound diabetes management may suggest a difficulty in accessing them or an under-appreciation for their value, until the consequences of poor control manifest.

Free or low cost medicines were an essential part of how people managed their diabetes. Other critical areas were support from family or friends, health education and information, and professional coordination of healthcare services amongst providers.

The study showed a general lack of availability of relevant information for patients within the clinicians' practices. Over half of all providers either did not have any information on diabetes and potential eye complications or within the available diabetes information that which was on eye complications was insufficient. From the provider perspective, one of the major barriers to optimising eye health beyond the patient's general lack of knowledge or awareness was the perception that they felt that an eye exam was either not important or that eye complications were unlikely.

In contrast, patients expressed a high concern about the onset of potential complications related to their diabetes. Amongst these, loss of vision was the most feared. Yet, awareness and concern do not always translate to action, as one in five respondents believed that vision problems were a normal part of ageing and some did not make any special efforts, such as regular screening, to prevent vision problems.

Ensuring a patient's health literacy, in terms of the management of their diabetes and preventative strategies to the onset of complications, is paramount to the overall improvement in health outcomes.



Guidelines and Protocols for the Detection and Management of Diabetes-Related Eye Disease

A lack of available information and guidance for patients is only one part of the story as it relates to the sound management of a person's diabetes condition. The study underlined a serious deficit in written protocols and guidelines for providers. One in five ophthalmologists cite the lack of standard guidelines or principles that could underpin universal guidelines on referrals and screening as a significant challenge for improving patient outcomes in DED.

The gap in access to, or application of, protocols and guidelines across all types of providers was serious and significant. Of particular concern was the finding that less than half of the providers either did not have access to protocols or, for some, the protocols available were not used.

Without the availability of printed patient education information, or formal protocols and guidelines for providers, it should not be surprising that the study found the frequency of regular clinician-patient discussions regarding eye health was sub-optimal. Less than half of the respondents had regular

discussions with their doctor, meaning either every visit, or multiple times per year, regarding the possibility of eye complications. An even more concerning finding was that over a quarter had either never discussed eye complications with their health care professional or did so only after the onset of vision loss symptoms.

The lack of written protocols and important guidelines relating to the diagnosis and treatment of DED must be of primary concern, particularly amongst providers who may not have the required training and experience. While international guidelines, such as the International Council of Ophthalmology Guidelines⁴⁵, can be accessed readily there appears to be a disconnect between the availability of the global guidelines and the application at a national practice level.

Gaps and Barriers to Eye Care and Referral

Eye examinations are a critical element in the patient care pathway and an important tool for the prevention of the onset of diabetes-related eye conditions. Two in three ophthalmologists reported that most of their patients present for screening when vision problems have already occurred, and sadly, for some patients it is too late for effective treatment.

Barriers and challenges that exist were not only the lack of information exchange, the minimal regular active discussions that occurred between the health care professional and the patient, and clinical and care guidelines. The study also revealed barriers that were related to capacity such as: long wait times to schedule an appointment with a specialist, the length of time required in the clinic on the day of the visit, limited availability of necessary health services, and the proximity of services available near one's home.

Summary



Although seventy-three percent of all providers reported to screen patients for DED, such screening predominantly took place in a clinic, and only a minority provided an outreach screening service, such as a mobile clinic.

Almost one in five respondents reported that there was limited local access to eye examinations near their home. Diagnosis and treatment delays may therefore in part be as a result of the limited number of trained ophthalmologists within country.

Other reported barriers included the high cost of care, the complexity, and inadequacy of the referral process, and the lack of professional coordinated care. Ophthalmologists specifically acknowledge the complex referral pathway and the lack of integrated care, and ineffective screening services as serious systemic challenges that contribute to poor patient outcomes in diabetic eye health.

Screening and Diagnosis

Health care providers have a central responsibility to provide guidance on prevention strategies to improve the overall management of diabetes to prevent the onset of complications. The delivery of education about complications and the necessary discussions about the impact on function, autonomy, and livelihood is a critical part of overall management.

Timing for initial eye exams for persons with diabetes varied depending upon the type of diabetes, but most providers recommended an initial eye exam at the time of diagnosis for, either type 1 or type 2. One in five providers recommend an eye exam for type 1 diabetes after a pre-determined time and this varied on a case-by-case basis. This approach was generally consistent amongst the different types of providers. Although relatively small in number, it is disquieting that some 4% of providers only recommend screening once symptoms had occurred.

Given that three in four providers recommend annual follow-up screenings, it was of concern that less than half of all providers sent reminders to their patients to schedule an appointment.

It was promising to find, in the absence of available information, regular discussions, and regular appointment reminders, there was not only a relatively high awareness of eye-related complications associated with diabetes amongst respondents, but most patients were receiving eye exams for DED on a regular basis.

This finding, though, should be interpreted with a level of consideration that, in large part, the patients who participated in the study were self-selected, and more likely to be engaged and motivated in the management of their diabetes including screening. The profile of an aware, informed, and engaged patient population is clearly associated with higher adherence to regular screening and a proactive preventative approach.

Diagnosis and Treatment of DED and DME

The number one challenge faced by two in three ophthalmologists, was the late diagnosis of DED or DME, hindering them from maximising patient outcomes. Beyond the late diagnosis and the perception that many of their patients present when visual problems had already occurred, ophthalmologists reported reimbursement restrictions on approved therapies and the inability of governments to cover patient costs as significant barriers.

More than half of the ophthalmologists reported that diabetes duration, high glucose levels, and the presence of co-morbidities influenced the treatment decisions of patients diagnosed with DR and DME. In addition, the age of a patient and their ability to adhere to recommendations were also significant influences.

Overall, almost two-thirds of those diagnosed with DED received some form of treatment with the most common being laser, followed by surgery, and anti-VEGF therapy. Ninety-one percent of those surveyed either had completed, or were still undergoing treatment. Over three-quarters felt that the treatment had been successful and either their vision had improved or their vision had at least stayed the same. A third of people with DED, who had not received any treatment, said that their doctor did not recommend treatment at that stage.

In patients with DME, 85% received treatment, including laser, anti-VEGF therapy, and surgery. Ninety-one percent had completed, or were still undergoing treatment, and most felt that the treatment was successful, including almost half who said that their vision had improved. In those who had not received treatment (11%), almost one-third said that their doctor did not recommend treatment whilst others stated a variety of reasons, including: they were still waiting for treatment, the treatment was too expensive or the treatment would not be effective.

Summary

A small number of respondents started but did not complete treatment for DED or DME. For those with DED who did not complete treatment the most common reasons were: the treatment was not effective, their eye doctor was located too far away or there was a general fear about the treatment. Forty-four percent of those with DME who did not complete treatment cited the cost of the treatment as a barrier, or that the treatment was not effective, and for almost a third the appointment times were inconvenient.

The majority (87%) of those with DME preferred a proactive treatment approach to prevent further vision loss rather than reactive treatment once further vision loss had occurred.



The level of relevant experience and training on the management of DED including DME, of ophthalmologists varied with one in five reporting no specific training on the diagnosis or treatment of DR and / or clinically significant DME. There is eagerness though for additional training, as three-quarters of ophthalmologists would be interested in further education and certification on DME, angiogenesis and anti-VEGF therapies.

Burden and Impact of DED and DME

It is important to reflect on the personal impact of living with diabetes, and the

everyday experiences one faces even without impaired vision. Respondents revealed that living with diabetes has multiple challenges, and this was made even more difficult due to a basic lack of knowledge about their diabetes, making the right choices to ensure a healthy daily diet, balancing multiple health appointments with competing day-to-day priorities, and overcoming stigma and discrimination. These diabetes-related challenges are additional to the normal daily responsibilities such as work and family obligations– which can at times require the ability to drive, read, type, cook, clean and ultimately the ability to see the task-at-hand.

Losing the ability to see or having it compromised, due to DED or DME, will likely impact the ability to execute everyday tasks. More than three quarters of patients with DED or DME, said that their vision was impaired, either slightly or significantly. Vision loss and impairment had a significant impact on the autonomy of respondents as well as their lifestyle choices. As examples, one in three had difficulties driving a car, a quarter had trouble working or keeping a job, and even completing basic household responsibilities, such as cooking or cleaning, became difficult.

Furthermore, vision loss resulted in a restricted social life of those surveyed with many challenges and uncertainties about their ability to travel, to undertake leisure activities, and sadly, to interact with family and friends.

It is rather concerning that for one in five vision loss, due to diabetes, ultimately made it more difficult for them to manage their underlying diabetes, including the ability to exercise. From a personal perspective, managing one's environment without the ability of sight should not be underestimated, yet likely to be a preventable situation.

DED and DME had a significant impact on people's lives and were associated with deterioration in physical wellness. Vision impairment and loss due to DED and DME, affected the ability to complete normal daily activities (64% of people with DME, and 58% with DED, experienced limitations compared to 37% of those without DED). A greater proportion of those with DED and DME rated their health as fair or poor compared with those without DED, and they reported a higher frequency of physically unhealthy days and restricted daily activities.

Importantly, for many people vision loss restricted their ability to undertake paid work, which has the potential of escalating the economic and social care burden, personally and on a larger scale, in light of increasing rates of diabetes worldwide. About two-thirds of all respondents did not receive any form of government assistance. However, where assistance was used, the most common type was medical and pension assistance. The proportion of respondents receiving government assistance increased, particularly income and food assistance, for those with DED and DME compared to those without DED.

While the study showed an association between increasing age and the need for assistance, overall it was most evident in those with DME.

For those in the youngest age group (18-39 years) almost half received some form of assistance compared with a third of those with DED and a quarter of those without DED. At the peak of one's normal working life (40-59 years) almost half (49%) of those with DME received assistance versus 41% with DED and 29% without DED.

The study also showed an association between the ability to pay for food and age, with a higher proportion of people in the younger age groups having difficulty paying for food at any time within the previous year. In people aged between 18 and 39 years, more than a quarter (28%) of those without DED, and almost a third (30%) with DED, had trouble paying for food compared with almost half (43%) of those with DME.

The global health care burden related to DED and DME identified in this study is significant and serious. Governments around the world have a unique opportunity and responsibility to develop proactive across-portfolio policies that respond sequentially to the social and economic consequences of a rapidly ageing population and the burgeoning diabetes epidemic.



69%

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



Recommendations

The recommendations presented below based on findings from the DR Barometer Study aim to optimise the outcomes for adults living with diabetes who are at risk of developing eye complications.

In alignment with the development of good evidence-based policy, the first set of recommendations focus on responding to several clear gaps in the research agenda. Following on, the recommendations broadly follow the patient care pathway starting with awareness and information, guidelines and protocols, screening and diagnosis, treatment of DED and DME and rehabilitation.

Research and Policy Agenda Setting

- Establish a cross-discipline, cross-border coalition platform to identify synergies and good practices for the improvement of diabetes-related eye health, and further the work and findings of the DR Barometer Study in order to improve standards and practices within health systems.
- Develop a new advocacy model comprising patients, diabetes, vision-related and ageing organisations, academia and clinicians, to address barriers and identify solutions at a national level in order to join up policy developments, foster intergovernmental dialogue within ministries with the end goal of developing a national strategy for diabetes-related eye complications.
- Establish a multi-sectorial, multi-disciplinary research consortium which aims to address the research gaps in the understanding of disease-specific modifiers or indicators within diabetes health, socio-economic implications of diabetes-related eye complications, and future translational research needed to achieve optimised patient outcomes and improved service provision.
- Identify good practices in joined-up care and patient education, to establish baseline approaches for patient care with the aim of replicating and scaling, as appropriate, with the health system characteristics within each country.
- Inform the United Nations Sustainable Development Goals (SDGs), particularly Goal 3 related to health and the promotion of universal health coverage which provides opportunities to include eye health services, the WHO Global Strategy and Action Plan on Healthy Ageing, the WHO Universal Eye Health global action plan, the NCD Alliance, and the Vision 2020 Action Plan of the social and economic consequences of diabetes-related eye complications.

Recommendations

Awareness and Information for the management of diabetes and diabetes-related eye complications

- Evaluate the uptake, and barriers, of patient support programmes, and the effectiveness of eye-related information within such programmes, to ensure appropriate access to education on lifestyle and behavioural interventions.
- Establish universal principles of information requirements of patients regarding diabetes-related vision loss and develop a suite of relevant patient education resources.
- Ensure clinical settings of all health care professionals, managing people with diabetes, are equipped with sufficient and suitable patient education information on diabetes-related eye complications. Information should be available in the patient's native language and provided upon initial diagnosis of diabetes and initial eye exam.
- Train clinical staff to engage patients in a proactive dialogue on the importance of eye health and preventative strategies, including adherence to an annual exam, as the new standard of clinical care. Training should be provided to all health care professionals including, nurses, dietitians, nutritionists and health educators.
- Develop, and pilot, a patient-centric checklist and personalized logbook, with relevant health information, including clinical data and recommendations, to facilitate communication between health care professionals in order to achieve an effective, holistic management of diabetes.

- Collaborate with stakeholders in a government endorsed national health campaign on the importance of vision in the overall management of diabetes, to raise eye health as a priority on a national platform, and if available, inform patients of national screening services.

Guidelines and Protocols

- National eye associations to develop a set of guidelines, for primary care providers and specialists, that include natural history of diabetic eye disease, recommended screening intervals, how to prepare the patient for screening, simple grading definitions, available treatment protocols, and further steps to ensure eye health. Uptake of these guidelines should be assessed on an annual basis and modifications made as appropriate.
- Ensure that diabetes-related eye complications are on the agendas of national and international medical congresses across disciplines and sectors.
- Investment in continuing education and training for all health care professionals, about the natural history of diabetes and its sequelae, including prevention strategies, advancements in available treatments, and the importance of rehabilitation services for those in need.



Screening and Diagnosis addressing Gaps and Barriers to Eye Care and Referral

- Assess health system barriers to eye exams and define a national strategy to ensure they are accessible and affordable to all patients regardless of their age, duration of diabetes, gender, level of education, place of residence or income level.
- Clinical practices to develop efficient and effective systems to provide patients, and where appropriate caregivers, with regular appointment reminders to ensure patients are able to attend their annual eye exam.
- Develop sound principles of an efficient, holistic patient-driven care system; ensure effective communication between relevant health care professionals, including the sharing of relevant patient data, toward optimising patient outcomes.
- Conduct cost-effectiveness and patient-reported outcome analyses on the value of a patient coordinator role to streamline the referral pathway, schedule appointments and coordinate follow-up care in order to determine the relevance, applicability and effectiveness within various healthcare systems.
- Study the disparities in access to care at a national level, such as proximity to available healthcare services, of various at-risk populations toward the development of national strategies and recommended actions to address identified inequalities.
- Strengthen human resources in eye care delivery and invest in the training of a new generation of eye care professionals, enhanced infrastructure and care-delivery resources, including mobile outreach and telemedicine, to alleviate the current capacity constraints in providing eye examinations and delivery of care.

- Conduct clinical efficiency assessments to optimise service provision, and eliminate redundancies and inadequacies in order to streamline the patient flow within a clinical setting.
- Consider the applicability of a government funded national eye screening service such as the United Kingdom National Health Service (NHS) Diabetic Retinopathy Screening Programme. Invest in the training and certification of grading technicians, diagnostic equipment and information technology (IT) platforms.

Treatment of DED and DME and Rehabilitation

- Inform patients of the results of their screening exam, their diagnosis, rationale if treatment is not recommended or of recommended treatment, protocol and relative expectations, and any further preventative measures to ensure they are an active participant in their medical care.
- Ensure patients have access to quality low-vision rehabilitation services and support programmes to ensure physical and mental health of people with DED or DME is not compromised.
- Conduct cost-effectiveness analyses comparing short term gains derived from reimbursement restrictions on approved therapies, or diagnostic exams, with long-term socio-economic impact and patient outcomes.
- Enhance advocacy efforts to ensure patients are not denied access to evidence-based treatment, or screening services, due to reimbursement restrictions or the inability to pay for services.



20%

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



Conclusion

The number of people with diabetes has nearly quadrupled since 1980 to 415 million adults today, and by 2040 is set to rise to 642 million, equating to roughly 10% of the global adult population aged between 20 and 79 years².

The WHO has also identified population ageing as one of the four main drivers of non-communicable disease, such as diabetes, in developing countries with one in five adults, aged 65 years and older, affected by diabetes with this group expected to reach 280 million by 2030^{46,47}.

Diabetes, coupled with population ageing, remains one of the largest global public health concerns of modern time and DR and DME are recognized as the leading causes of blindness in the working age population of most developed countries and account for 1% of blindness worldwide^{44,45}.

The timing of these demographic and disease-specific drivers has created a perfect storm catapulting vision loss, due to diabetes, into a major global health concern representing a significant burden for health and social systems, as well as individuals and families. Preventative strategies that are clearly defined, adequately resourced, implemented, monitored, and evaluated for their effectiveness are urgently needed.

Determining and addressing the current gaps in the patient care pathway are essential to preventing unnecessary blindness and visual impairment in people with diabetes due to DED. Large-scale public health initiatives are needed to strengthen the capacity of health systems and organisations to promote the prevention of DED and to improve access to screening and treatment.

Strategic investments are essential to ensure necessary training for increased numbers of health care professionals, to develop cost-effective interventions, to improve compliance, and to build sustainable business models for improved outcomes in eye health for those living with diabetes.

The DR Barometer Study findings and recommendations are intended to inform the development of improved clinical management of diabetes and screening for DED as well as the implementation of national health policies to address the evidenced systemic barriers.

The global healthcare burden related to DED and DME identified in this study is significant and serious. From the deeply private level of a person who can no longer assume family responsibilities and is dependent on the state for income assistance to the national impact whereby millions of working-age citizens are unable to be part of the labour force. Governments are encouraged to use the unique findings of the DR Barometer Study to invest in a brighter future for people with diabetes.

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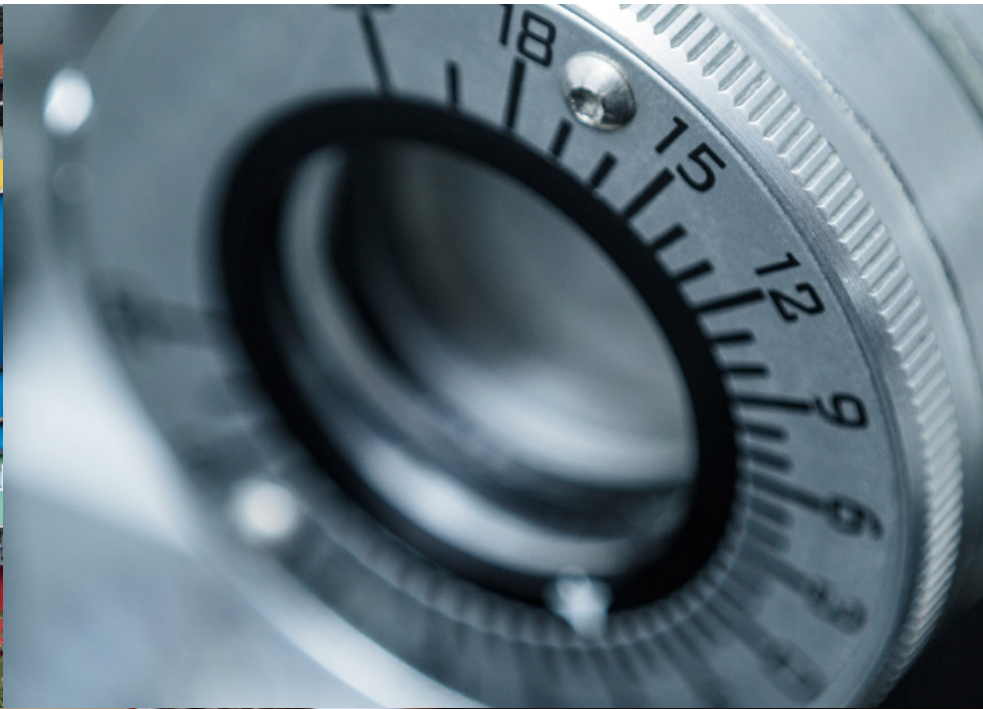
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DRBarometer.com

Title: The Diabetic Retinopathy Barometer Report Global Findings
Format: Electronic book
This publication has been assigned: 978-0-9688407-2-6