

Opportunities to improve clinical management of diabetic retinopathy and diabetic macular edema: Insights from global survey data of patients, providers, and clinic staff from 24 countries

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Focke Ziemssen: Travel grants and personal fees: Allergan/AbbVie, Alimera, Bayer Healthcare, Biogen, Boehringer Ingelheim, Clearside, Janssen, Novartis, Novo Nordisk, MSD Sharp & Dohme, Regeneron, Roche/Genentech, Sanofi, Sandoz, Stada.

Michelle Sylvanowicz: Employee: Bayer.

Winfried M Amoaku: Advisory board membership: AbbVie, Alcon, Alimera, Allergan, Apellis, Bayer, Bausch + Lomb, Bioeq, Novartis, Pfizer; Speaker fees: Alimera, Allergan, Bayer, Novartis, Pfizer; Support for travel: Alimera, Allergan, Bayer, Novartis, Pfizer; Research sponsorship and funding: Allergan, Bayer, Boehringer Ingelheim, CenterVue, Gyroscope, Novartis, Optos.

Tariq Aslam: Consultant: Bausch & Lomb, Bayer, Laboratoires Théa Pharmaceuticals, Novartis, Oraya, Roche.

Bora Eldem: Consultant: Allergan, Bayer, Novartis, Roche.

Robert P Finger: Research grant: CentreVue, Heidelberg Engineering, Novartis, Zeiss; Consultant: Alimera, Allergan, Bayer, Ellex, Inositec, Novartis, Opthea, Roche/Genentech, Santhera; Support for travel: Novartis.

Richard P Gale: Consultant/advisory boards: Allergan, Alimera, Bayer, Novartis, Santen; Educational travel grants: Allergan, Bayer, Heidelberg, Novartis; Research grants: Allergan, Bayer, Novartis, Roche.

Laurent Kodjikian: Consultant: AbbVie, Alcon, Allergan, Bayer, Krystal Biotech, Novartis, Regeneron, Théa.

Jean-François Korobelnik: Consultant: AbbVie, Apellis, Bayer, Janssen, NanoRetina, Roche, Thea, Carl Zeiss Meditec; Member of Data Safety Monitoring Board: Alexion, Novo Nordisk.

Xiaofeng Lin: Consultant: Bayer.

Anat Loewenstein: Consultant: Allergan, Bayer, Beyeonics, Forsight Labs, Notal Vision, Novartis, Roche.

Paul Mitchell: Consultant: Allergan, Bayer, Novartis; Steering Committee member: Bayer.

Moirá Murphy: Employee: Exploristics, Ltd.

David R Owens: Consultant: Bayer.

Nick Parker: Employee: The International Agency for the Prevention of Blindness.

Ian Pearce: Lecture fees: Allergan, Bayer, Heidelberg, Novartis; Consultant: Allergan, Alimera, Bayer, Novartis, Support for travel: Allergan, Bayer, Novartis.

Francisco J Rodriguez: Consultant: Bayer, Novartis, Roche; Speaker: Bayer, Novartis, Roche; Research funding: Novartis.

Jude Stern: Employee: The International Agency for the Prevention of Blindness.

S James Talks: Advisory board member, speaker fees, and research support: Bayer, Novartis; Research grants: Boehringer Ingelheim, Roche; Consultant: Bayer.

David T Wong: Grants/research support: Bayer, Novartis, Roche; Consultant: Alcon, Allergan, Apellis, Bausch Health, Bayer, Novartis, Roche, Topcon, Zeiss; Equity: Arctic DX.

Tien Yin Wong: Consulting fees/travel support/review fees: Aldropika Therapeutics, Bayer, Boehringer Ingelheim, Genentech, Iveric Bio, Novartis, Oxurion, Plano, Roche, Sanofi, Shanghai Henlius; Stock: EyRIS.

Jane Barratt: Consultant: Bayer.

Acknowledgments and funding: This survey was sponsored by Bayer Consumer Care AG, Basel, Switzerland. Medical writing support, under the direction of the authors, was provided by ApotheCom and funded by Bayer Consumer Care AG, Basel, Switzerland, in accordance with Good Publication Practice (GPP4) guidance (*Ann Intern Med.* 2022;175:1298–1304).



Problem: There are significant challenges, such as adherence to treatment, clinic capacity constraints, and financial limitations, associated with routine clinical management of DR and DME that may impact patient treatment and outcomes^{1–3}



Objective: To improve understanding of the barriers to good clinical management of DR and DME from the perspectives of patients with DR/DME, providers, and clinic staff



Outcome: Quantifying known and unknown barriers to identify meaningful evidence-based actions in order to improve eye care of patients with DR/DME



Survey design: Multi-country paper-based survey of patients, providers, and clinic staff

- **Patients with DR/DME:** 39 and 41 questions on personal characteristics, disease information, challenges with appointments, treatment experiences, and opportunities to improve support
 - The DME survey also explored treatment adherence^{a,4}
- **Providers** (who administer and/or prescribe anti-VEGF treatment): 27 questions on similar topics from their perspective
- **Clinic staff** (who do not administer and/or prescribe anti-VEGF treatment): 18 questions on similar topics from their perspective

^aDefined as missing ≤ 1 appointment over the course of a year. A visit is considered missed if the recommended appointment date is exceeded by >2 weeks for any reason.

The results of the nAMD survey are not presented here. People with diabetes includes patients with DR and patients with DME.

DME, diabetic macular edema; DR, diabetic retinopathy; VEGF, vascular endothelial growth factor.

1. Kern C, et al. *Graefes Arch Clin Exp Ophthalmol* 2021;259:1289–1296. 2. Cicinelli MV, et al. *Indian J Ophthalmol* 2020;68:316–323. 3. Okada M, et al. *Ophthalmol* 2021;128:234–247. 4. Okada M, et al. *JAMA Ophthalmol* 2021;139:769–776.

DR Barometer
Shifting the needle
DR Barometer Survey
Diabetic Macular Edema
Patient Survey

Patients with DME

WHAT IS THE DR BAROMETER PROGRAMME?
The DR Barometer is a programme dedicated to improving the vision health of people living with diabetes...
The survey has been developed by a group of experts that includes doctors and leaders from patient groups, in partnership with Bayer Pharmaceuticals...
The results will help to develop:
Resources and tools to help support people living with DME
Guidance and tools to support doctors and staff who treat people living with DME

DO YOU QUALIFY FOR THIS SURVEY?
Firstly, it is important to make sure you qualify. This survey is intended for people who:
Have been diagnosed with Diabetic Macular Edema (DME)
Have been diagnosed with Diabetes Mellitus (DM)

Each statement is an opportunity to better support you in speaking to your DR appointment.
Please rate the following statements on the following scale:
1=Not at all important; 2=Somewhat important; 3=Important; 4=Very important

Statement	1	2	3	4
My general diabetes management is discussed in the clinic	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My general diabetes management is discussed by my GP	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My general diabetes management is discussed by my optician	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My general diabetes management is discussed by my pharmacist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My general diabetes management is discussed by my other healthcare professionals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

DR Barometer
Shifting the needle
DR Barometer Survey
Provider Survey

Providers

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DO YOU QUALIFY FOR THIS SURVEY?
Firstly, it is important to make sure you qualify. This survey is intended for people who:
Are a General Practitioner (GP), Diabetes Specialist, Nurse, Diabetes Health Educator, Local patient organization services, Peer to peer support groups, Other patients in the waiting room, Family and / or friends, Generic disease information websites (e.g. Google, Wikipedia), International patient organization's websites (e.g. International Diabetes Federation), Pharmaceutical company's websites, Social media (e.g. Facebook, Twitter, Podcasts)

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Guidance and tools to support doctors and staff who treat people living with DR

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Have been diagnosed with Diabetic Retinopathy (DR)

Each statement is an opportunity to better support you in speaking to your DR appointment.
Please rate the following statements on the following scale:
1=Not at all important; 2=Somewhat important; 3=Important; 4=Very important

Statement	1	2	3	4
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My general diabetes management is discussed by my optician	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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DR Barometer
Shifting the needle
DR Barometer Survey
Allied Health Professional Survey

Clinic staff

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Guidance and tools to support doctors and staff who treat people living with DME

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My general diabetes management is discussed by my other healthcare professionals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

13. Have you ever proactively sought additional information from any of these sources to better understand your DME and/or your eye treatment? If so, please rate the usefulness of these resources on the following scale: 1=Not at all Useful; 2=Somewhat Useful; 3=Very Useful. If you have not used the resource, check the box on the far right.

Resource	1	2	3	Have Not Used This Resource
Regular General Practitioner / Family Doctor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Diabetes Specialist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nurse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Diabetes Health Educator	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Local patient organization services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Peer to peer support groups	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other patients in the waiting room	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family and / or friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Generic disease information websites (e.g. Google, Wikipedia)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
International patient organization's websites (e.g. International Diabetes Federation)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
International Diabetes Federation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pharmaceutical company's websites	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social media (e.g. Facebook, Twitter, Podcasts)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

14. Do you receive the same guidance and information from your General Practitioner/Family Doctor and/or Diabetes Specialist as compared to your eye doctor on how to manage your diabetes and your DME?

The information I receive is always different depending on which doctor I am speaking to

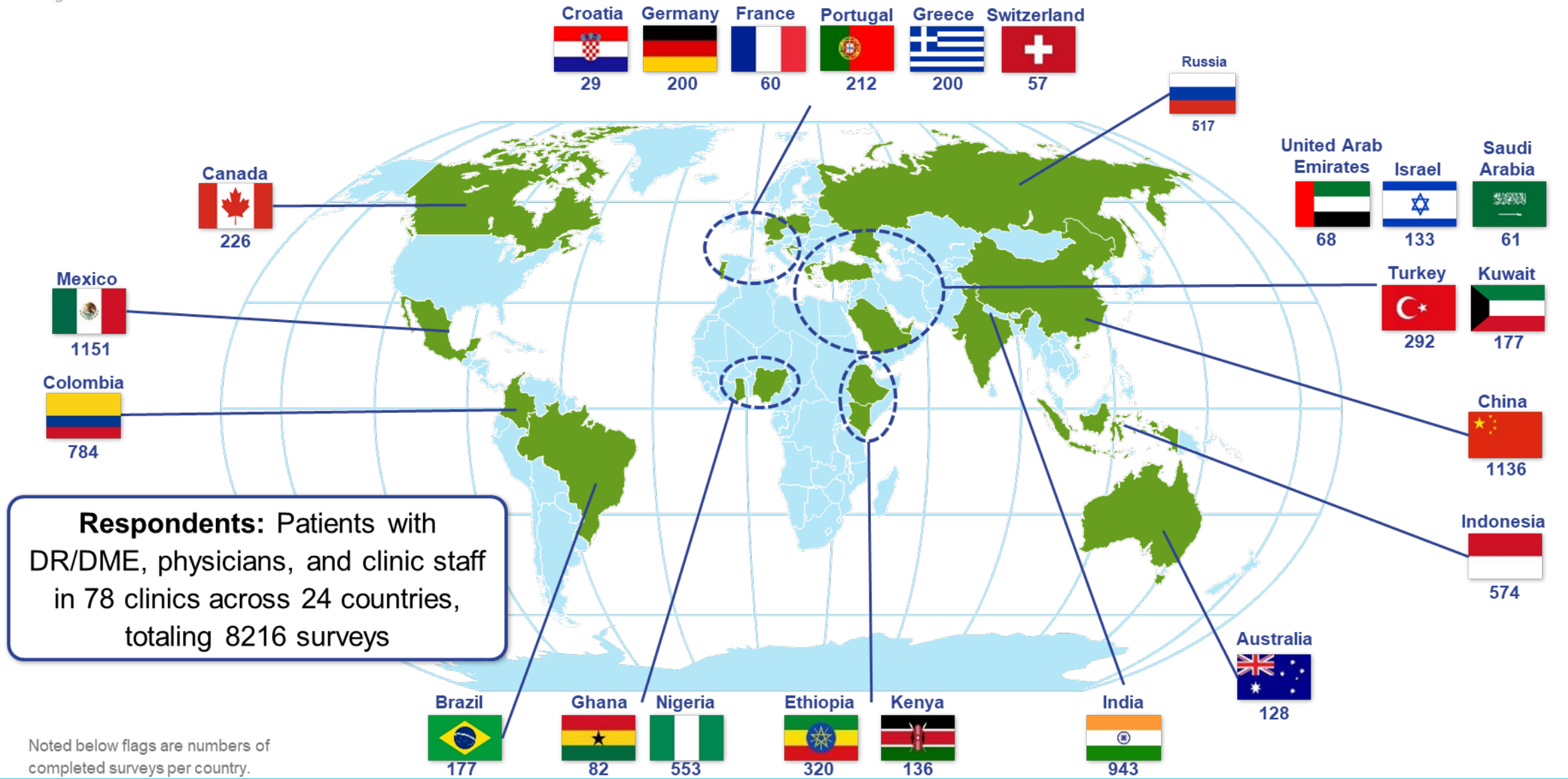
The information is sometimes the same, but I am still not sure which information is correct

The information I receive is always the same regardless of which doctor I am speaking to

Likert-scale questions

Single-choice questions

Global Survey: respondents for the DR/DME survey



Respondents: Patients with DR/DME, physicians, and clinic staff in 78 clinics across 24 countries, totaling 8216 surveys

Noted below flags are numbers of completed surveys per country.

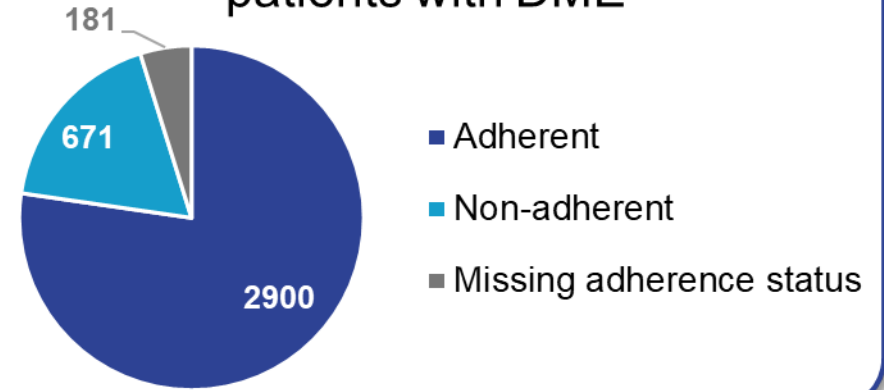


Data: 8216 respondents comprising:

- 3752 patients with DME
- 2535 patients with DR
- 680 providers
- 1249 clinic staff



Self-reported adherence of patients with DME^a



Adherence: 17.9% of patients with DME were non-adherent^a. Of these:

- **46.9%** missed 2 appointments
- **32.9%** missed 3 appointments
- **20.1%** missed ≥ 4 appointments

^aAdherent defined as missing 1 or fewer appointments over a 1-year period; non-adherent defined as missing ≥ 2 appointments over a 1-year period.

No statistical comparisons were planned or performed; survey data were analysed and are reported descriptively.

For patients with DME:



28.7% reported **not really understanding** their disease and/or treatment



41.1% were **unsure how long** treatment would be required



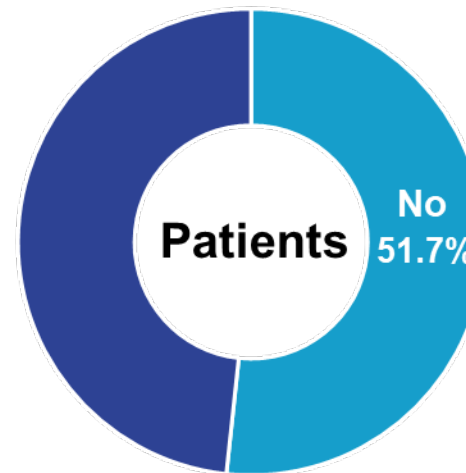
41.6% did not know **how many more treatments** they were likely to receive in the next 12 months



27.9% said they are **not sure if the treatment is working** as their vision is either not better, or is worse

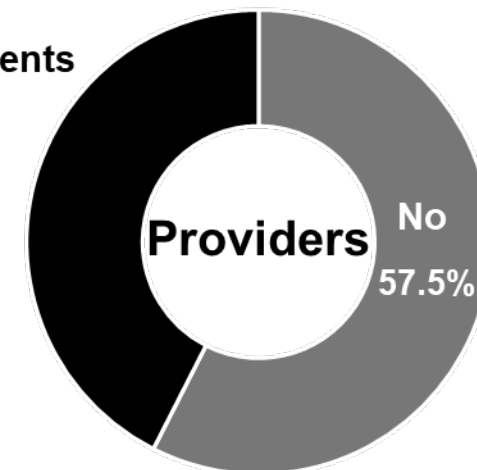


26.3% thought that their treatment was successful and **no longer needed**



Did you receive clear information about what DME is and what to expect over time with treatment?

Do you have clear information for patients about what DME is, and what to expect with treatment?



How often do providers always discuss key topics with patients in the first 3 months following diagnosis?



Disease

The risk that DR/DME can result in **vision loss** (59.9%)

The correlation between **diabetes and risk of complications** (58.4%)

A **basic explanation** of DR/DME (57.2%)

How **improving diabetes control** can reduce disease progression (56.2%)



Treatment

How often patients will need treatment (41.6%)

What to expect with vision change **over time** with treatment (40.3%)

How long treatment may be needed for (39.3%)

What to expect after **completing** a year of treatment (26.5%)



Support

How to include **family or friends** in the patient's care (23.7%)

Where to find more information on **diabetes management** (21.9%)

How to access more information on **DR/DME or support services** (19.6%)

Are we missing an important part of the appointment burden story?



For patients with DME:

42.8% said that there were **too many diabetes appointments**

45.0% said that there were **too many eye appointments**

When patients were asked about challenges with managing DME:



52.5% were **concerned about being a burden** to family/friends



51.7% said that the **frequency of treatment** can be too much



57.6% spent between **2 and 6 hours** attending appointments



48.4% found it **difficult to travel to the clinic** (cost/ability/distance)



49.2% had additional **out-of-pocket costs**



40.8% said that it was **hard for their accompanying person** to attend

Opportunities identified by patients to better support them with DME



In the clinic

My doctor proactively discussing challenges I may face (83.7%)

Always having the same clinic team treating me (83.0%)

Appointment reminders sent by the clinic (80.4%)

Dedicated nurse in the clinic to provide guidance on DME and diabetes (75.2%)

Providing diabetes care services within the eye clinic, and vice versa (75.1%)

Ability to monitor my vision accurately with a home monitoring machine (67.0%)



Access to treatment

Longer time between treatments without losing vision (74.3%)

Phone consultations to answer questions I may have (77.6%)

Medical services/treatment that travel to/near my home (69.1%)



Financial assistance

With DME/drug prescription costs (73.1%)

With office/parking fees (57.4%)

How can these novel findings enhance patient-focused care?

This survey provides **unique, quantifiable insights** into the **scale and breadth** of the key challenges patients face from various perspectives. The persistent worldwide **appointment and disease burden** uncovered in these data should be perceived as an **opportunity to improve clinical management of DR/DME** by:



Improving patient understanding and access

- **Better educational material** for patients with DR/DME
- **Improved availability** of this material in the clinic



Setting patient expectations

- **Early and regular delivery of information** by providers on disease, treatment, and support
- **Upskilling** of providers and clinic staff to better communicate disease, burden, and support topics



Reducing disease and appointment burden

- Longer-duration therapies and treatment interval extensions, **reducing the burden** on the patient and the clinic
- **Better use of patient waiting time** as an opportunity to provide additional services or information
- **Additional financial support** to reduce the burden of appointment attendance

Survey centers:

Australia: Sydney West Retina, Australian Eye Specialists, Retina Specialists Victoria. **Brazil:** Hospital Oftalmologico de Sorocaba, Hospital de Olhos de Araraquara, Centro de Referência em Oftalmologia, Centro Brasileiro da Visão. **Canada:** Unity Health Toronto, Retina Centre of Ottawa, Eye Care Centre NB. **China:** Zhongshan Ophthalmic Center of Sun Yat-sen University, Shanghai General Hospital, The First Affiliated Hospital of Dalian Medical University, The First Affiliated Hospital of Kunming Medical University, Henan Provincial People's Hospital, Xi'an People's Hospital. **Colombia:** Fundacion Oftalmologica Nacional, Clínica Oftalmológica del Caribe, Clínica Oftalmologica Unigarro, Cali Ophthalmology Clinic, Clínica Foscal. **Croatia:** KBC Zagreb. **Ethiopia:** Biruh Vision Specialized Eye Care Center, Nisir Specialized Eye Clinic, La Vista Speciality Eye Clinic, Roha Specialized Eye Clinic. **France:** Hôpital de la Croix Rousse, Centre PO2 (Pôle Oise Ophtalmologie), Centre Rétine Gallien. **Germany:** Universitätsklinikum Tübingen, Universitätsklinikum Bonn, Augenzentrum am St Franziskus-Hospital, Klinikums der Universität München. **Ghana:** Tamale Teaching Hospital. **Greece:** Ophthalmological Clinic Of University Hospital of Alexandroupolis. **India:** Shroff Charity Eye Hospital, ICARE Eye Hospital, Synergy Eye Care, Prakash Netra Kendra, Narayan Netralaya Eye Hospital, Hyderabad Eye Research Foundation, L V Prasad Eye Institute, Sankara Nethralaya. **Indonesia:** JEC Eye Hospitals & Clinics, Netra Klinik Spesialis Mata – Bandung, RS Khusus Mata Prov. Sumatera Selatan, Sumatera Eye Center. **Israel:** The Medical Research, Infrastructure, and Health Services Fund of the Tel-Aviv Medical Center. **Kenya:** City Eye Hospital, Eldo Eye Clinic, Lighthouse for Christ Eye Center. **Kuwait:** Kuwait Specialized Eye Center. **Mexico:** Asociación para Evitar la Ceguera en México, Dr Roberto Nettel Flores General Hospital, Fundación Hospital Nuestra Señora de la Luz IAP, Instituto Mexicano de Oftalmología IAP, Sala Uno Ophthalmological Center. **Nigeria:** Department of Ophthalmology, Department of Ophthalmology University of Uyo Teaching Hospital, Uyo, MDR - Lighthouse Medical Eye and Specialist Laser Center Lokoja, Department of Ophthalmology, Jos University Teaching Hospital, Jos, Eye Clinic, Department of Ophthalmology, Faculty of Clinical Sciences, Ahmadu Bello University Zaria, University College Hospital Ibadan, Eye Foundation Hospital. **Portugal:** ALM – Oftamologia Médica e Cirúrgica, Centro Hospitalar de Setúbal, Centro Hospitalar e Universitário de Coimbra, Centro Hospitalar Universitário do Porto. **Russia:** National Medical and Surgical Center N.I. Pirogov, Ufa Research Institute of Eye Diseases, S. Fyodorov Eye Microsurgery Federal State Institution (Orenburg branch), Novosibirsk State Region Clinic Hospital. **Saudi Arabia:** King Abdulaziz Medical City. **Switzerland:** Swiss Visio Montchoisi. **Turkey:** Hacettepe University, Ankara City Hospital, Gaziantep University, Karadeniz Technical University Faculty of Medicine. **United Arab Emirates:** Medcare Eye Center, Moorfields Hospital Abu Dhabi.

Acknowledgments:

The survey was conducted by Exploristics Ltd, Northern Ireland, and was funded by Bayer Consumer Care AG, Basel, Switzerland.

Medical writing support was provided by ApotheCom, under direction of the authors, and was funded by Bayer Consumer Care AG, Basel, Switzerland, in accordance with Good Publication Practice (GPP4) guidance (*Ann Intern Med.* 2022;175:1298–1304).



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