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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DR Barometer
Shifting the needle

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nAMD Barometer
Overcoming Barriers

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Survey objectives and design

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

[a]Defined 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.

Individual questionnaires for respondents

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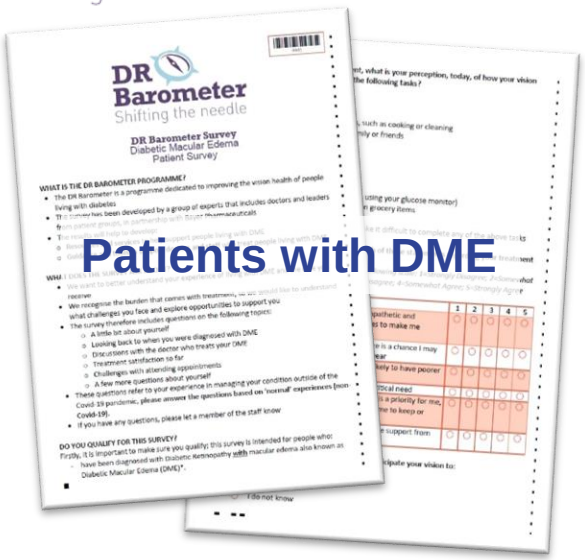
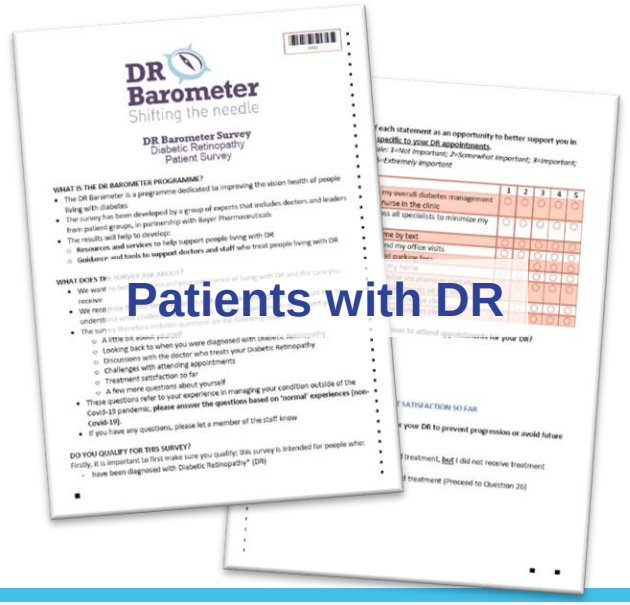
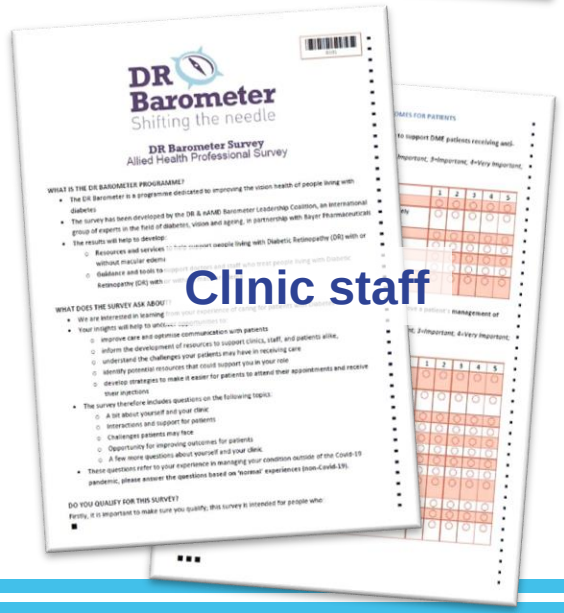


Patients with DME

Providers



Patients with DR



Clinic staff

Likert-scale questions

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 follo
2=Somewhat Useful; 3=Very Useful
If you have not used the resource, check the box on the far righ

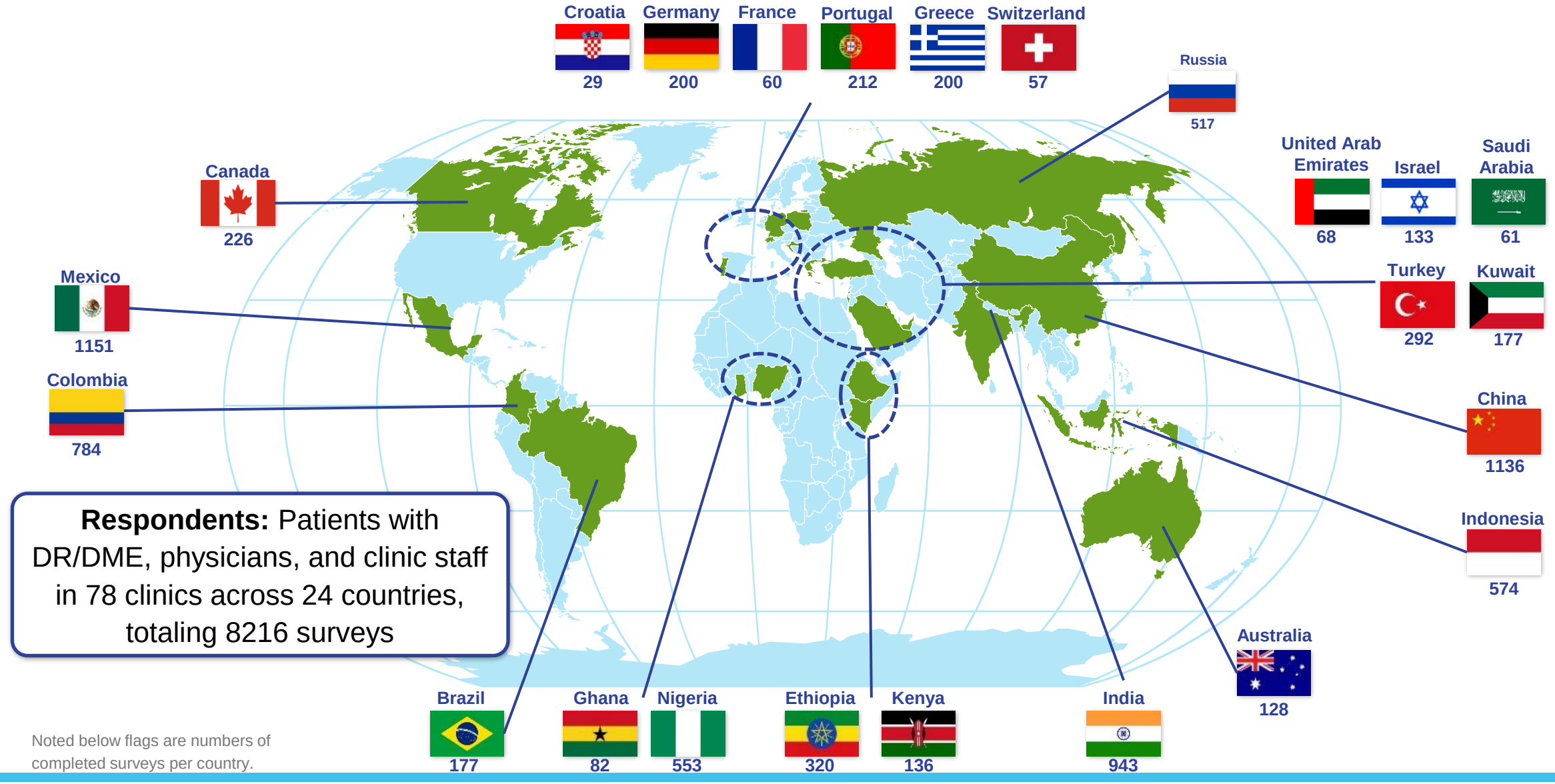
	1	2	3	Have Not Used This Resource
Regular General Practitioner / Family Doctor	○	○	○	○
Diabetes Specialist	○	○	○	○
Nurse	○	○	○	○
Diabetes Health Educator	○	○	○	○
Local patient organization services	○	○	○	○
Peer to peer support groups	○	○	○	○
Other patients in the waiting room	○	○	○	○
Family and / or 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)	○	○	○	○

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

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

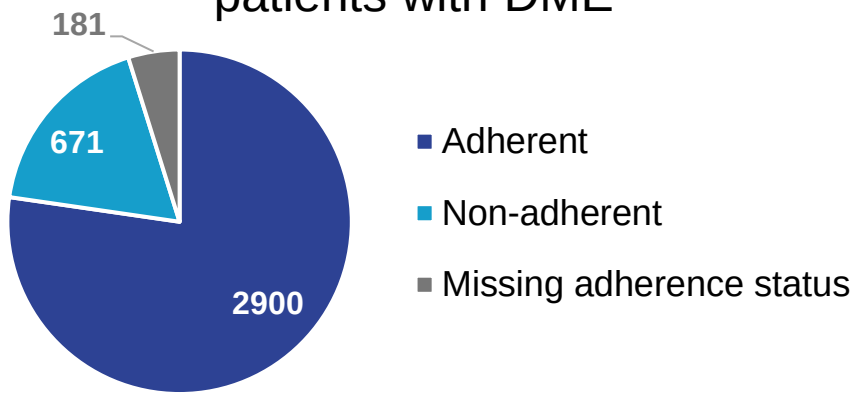
Noted below flags are numbers of completed surveys per country.

Survey participation and analysis

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

[a]Adherent 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.

Do patients understand their disease and treatment?

For patients with DME:

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

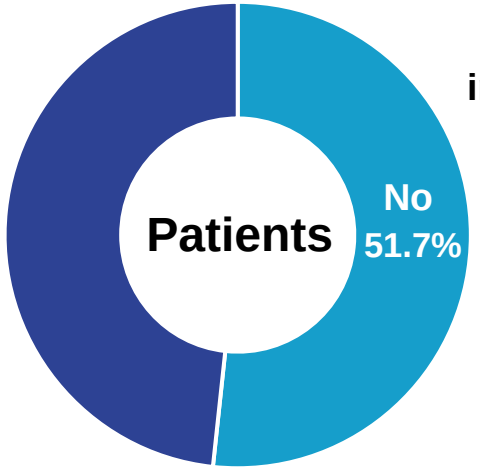
41.1% were **unsure how long** treatment would be required

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

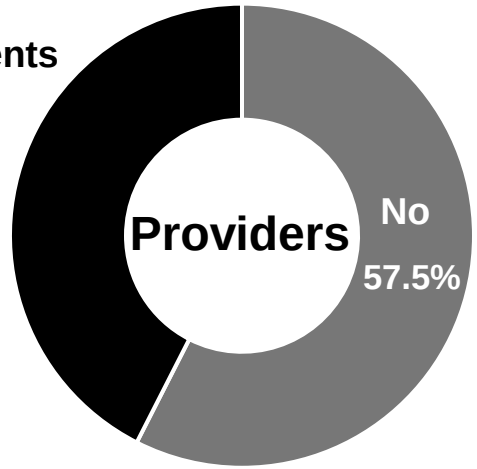
27.9% said they are **not sure if the treatment is working** as their vision is either not better, or is worse

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?



Grouped in the other half of the donut graphs are patients who did receive clear information about their disease and treatment, or providers who had this information available for patients, and those who did not remember or did not answer.

Patient survey results

Provider surv

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%)

Provider survey results

Providers were asked how frequently they discuss key topics concerning disease, treatment, and support; data reported for response "always discuss".

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

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Patient survey results

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

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

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

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

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

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

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Opportunities identified by patients to better support them with DME

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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%)**

Patient survey results

Percentages reported for patients rating the opportunity as “extremely important” and “very important”.

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

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