

Exploring the patient pathway from first symptoms to diagnosis: Results from an international survey of patients with myelin oligodendrocyte glycoprotein antibody-associated disease (MOGAD)

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Please use this QR code to download a PDF of the poster and the patient survey questions.

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Purpose

- To conduct an online survey of patients with myelin oligodendrocyte glycoprotein (MOG) antibody-associated disease (MOGAD) and caregivers to explore their perspectives on the experience from onset of first symptoms to final MOGAD diagnosis

Introduction

- MOGAD is a rare, inflammatory, demyelinating condition increasingly recognised as a distinct rare disease^{1–3}
- Low disease awareness and varied access to the MOG antibody test across regions/countries means that early diagnosis of MOGAD can be challenging
- Understanding patients' and caregivers' perspectives on symptoms experienced and healthcare interactions leading up to diagnosis is critical to address unmet patient needs in the diagnostic pathway

Methods

Survey design and administration

- Twenty-three multiple-choice and free-text questions were distributed by The MOG Project patient organisation to their patient network via an online survey
 - Scan poster QR code for full survey
- Anonymised responses (collected 18 January to 01 March 2022) were collated using QuestionPro⁴ software
- For simplicity, 'respondents' refers to all patients (self- or proxy-reported)

Results

Survey respondent demographics

- Responses were received from 21 countries; 68% of respondents (138/204) were from the United States (**Figure 1**)
- MOGAD diagnosis was most often made at <10 years or between 30 to 49 years of age (**Figure 2**)

Presentation of symptoms

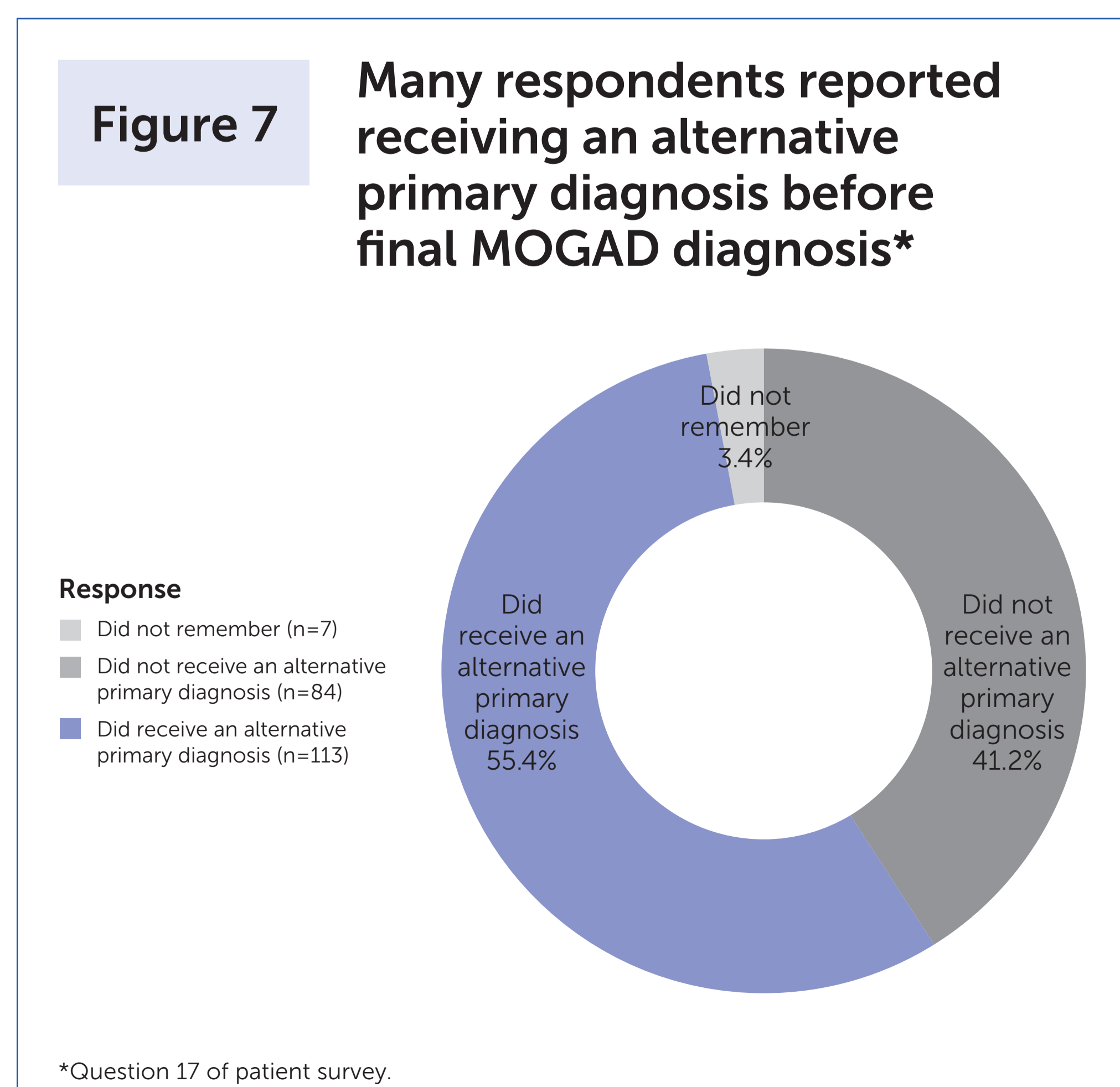
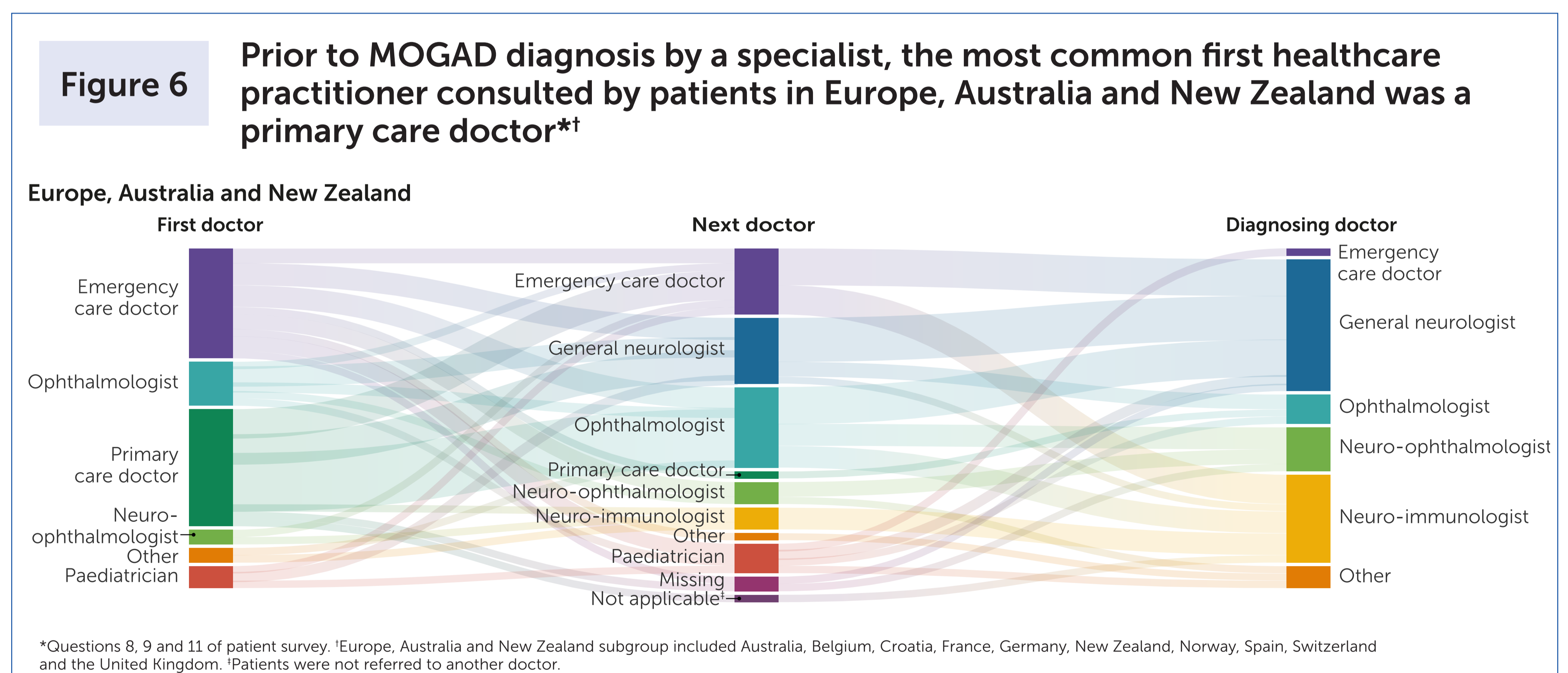
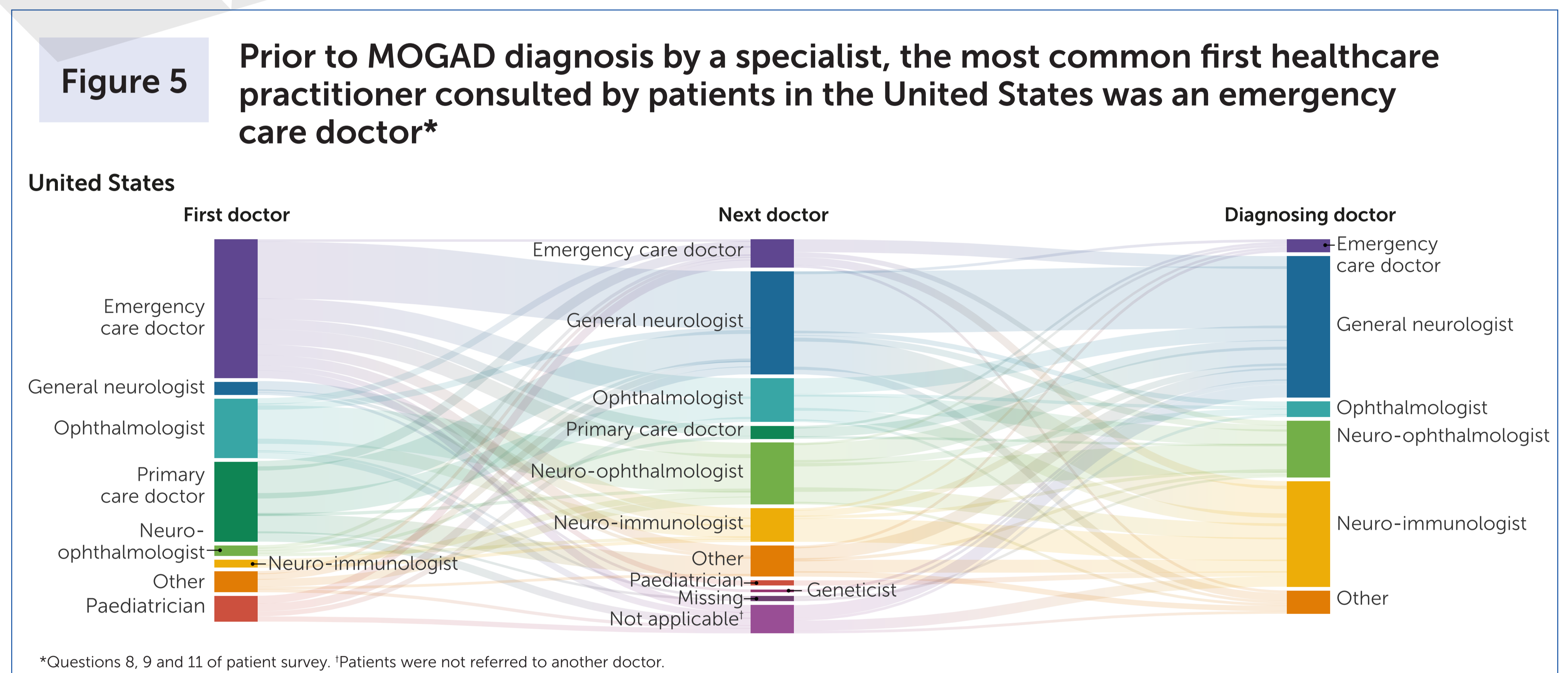
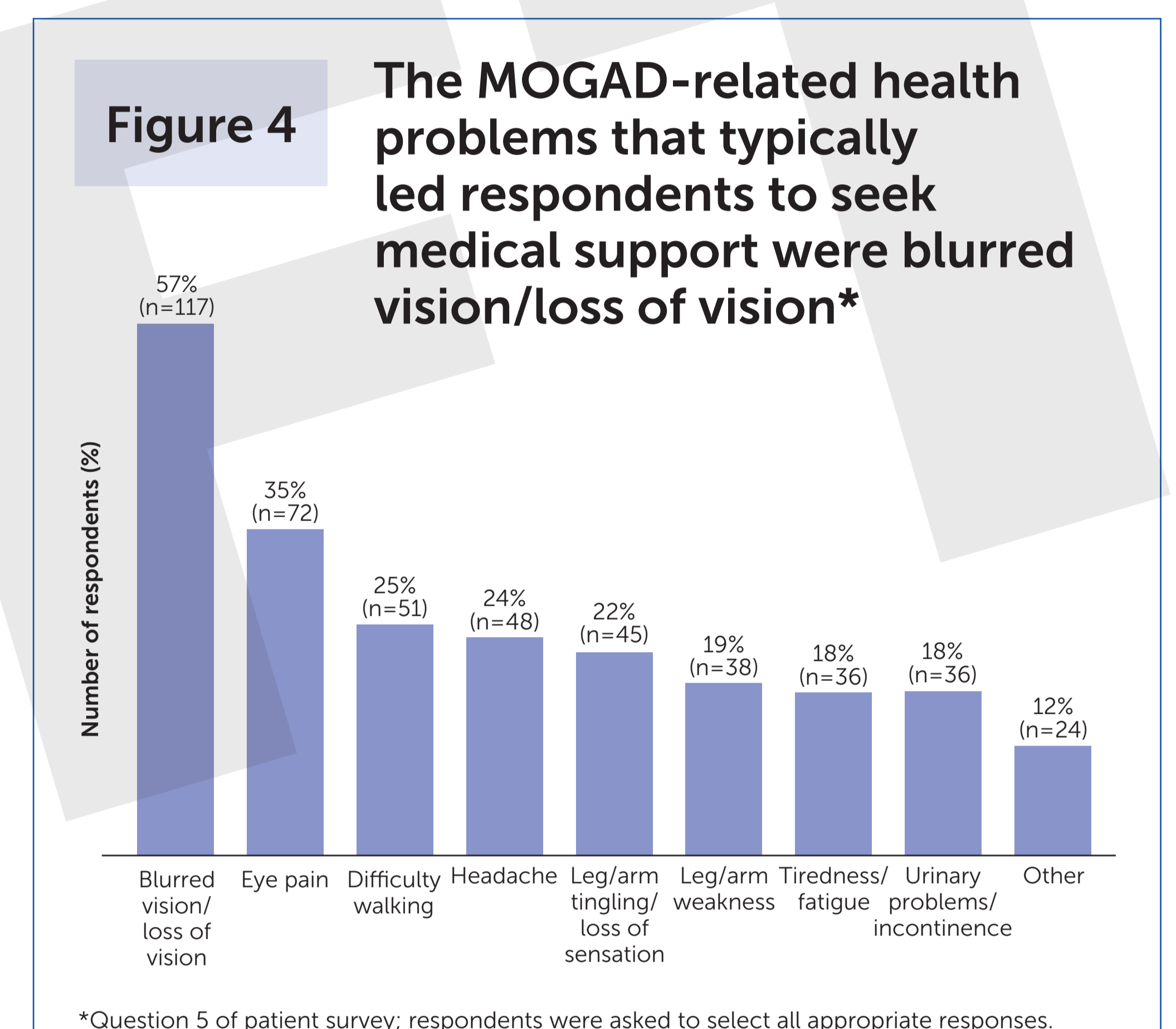
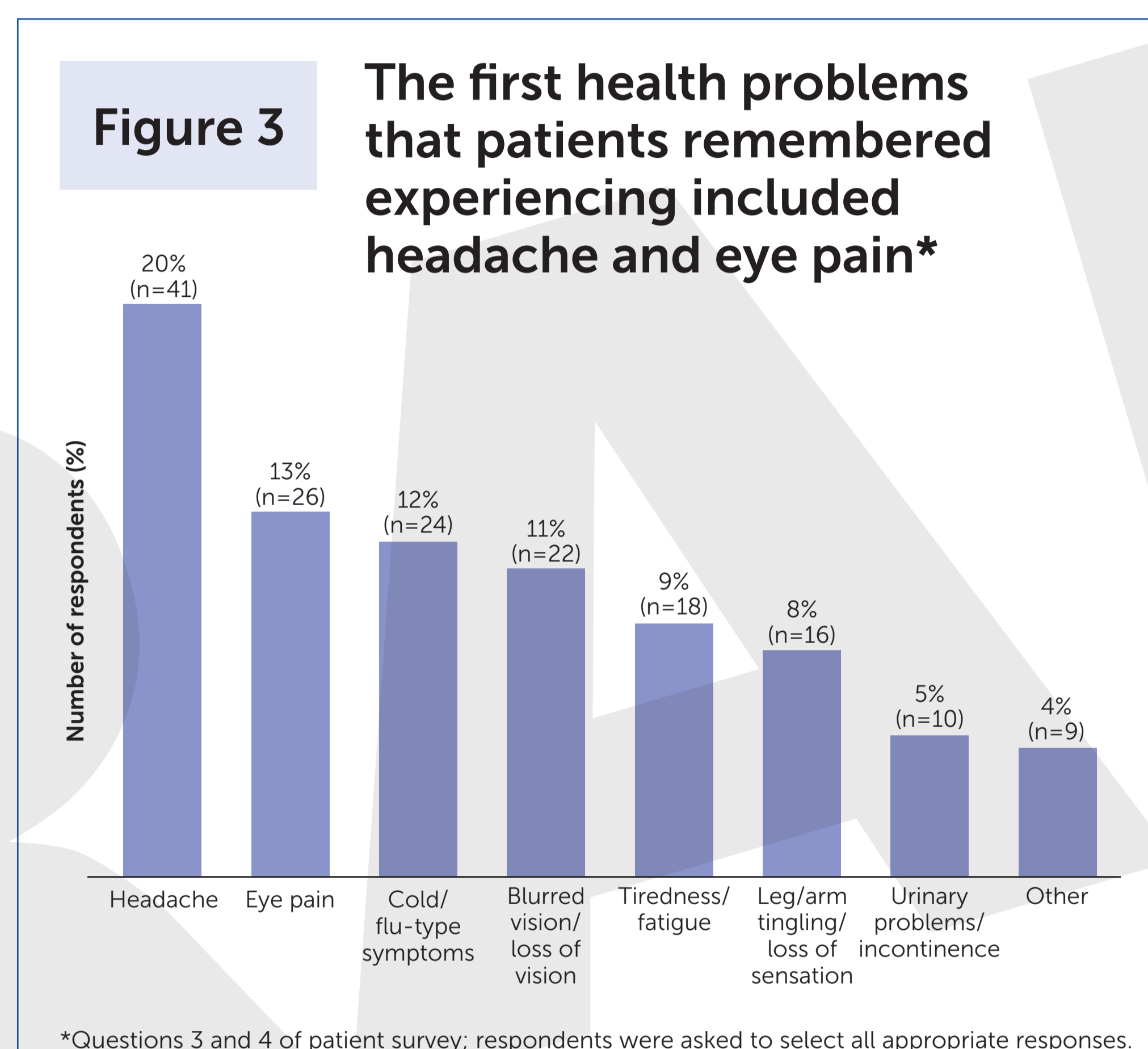
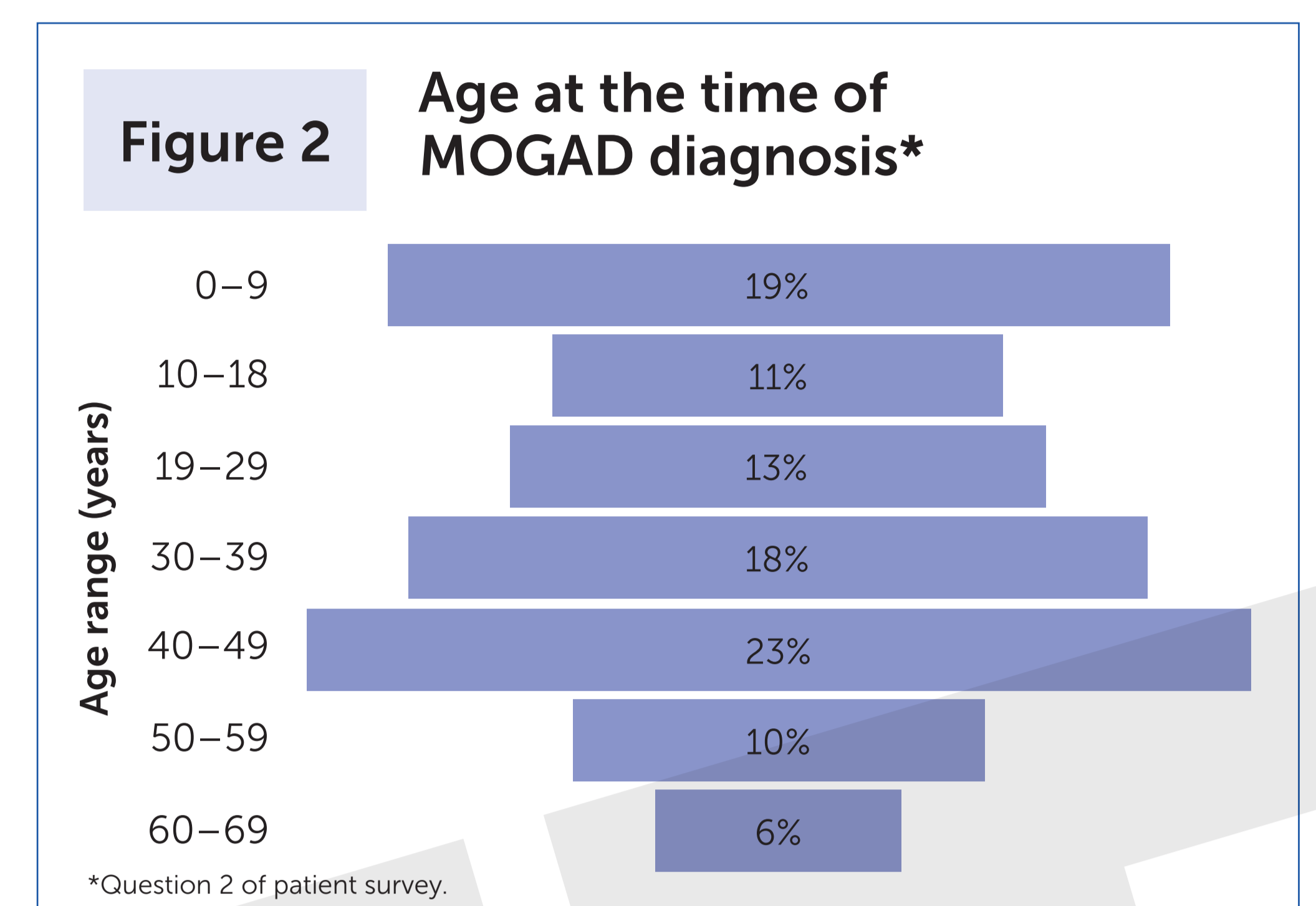
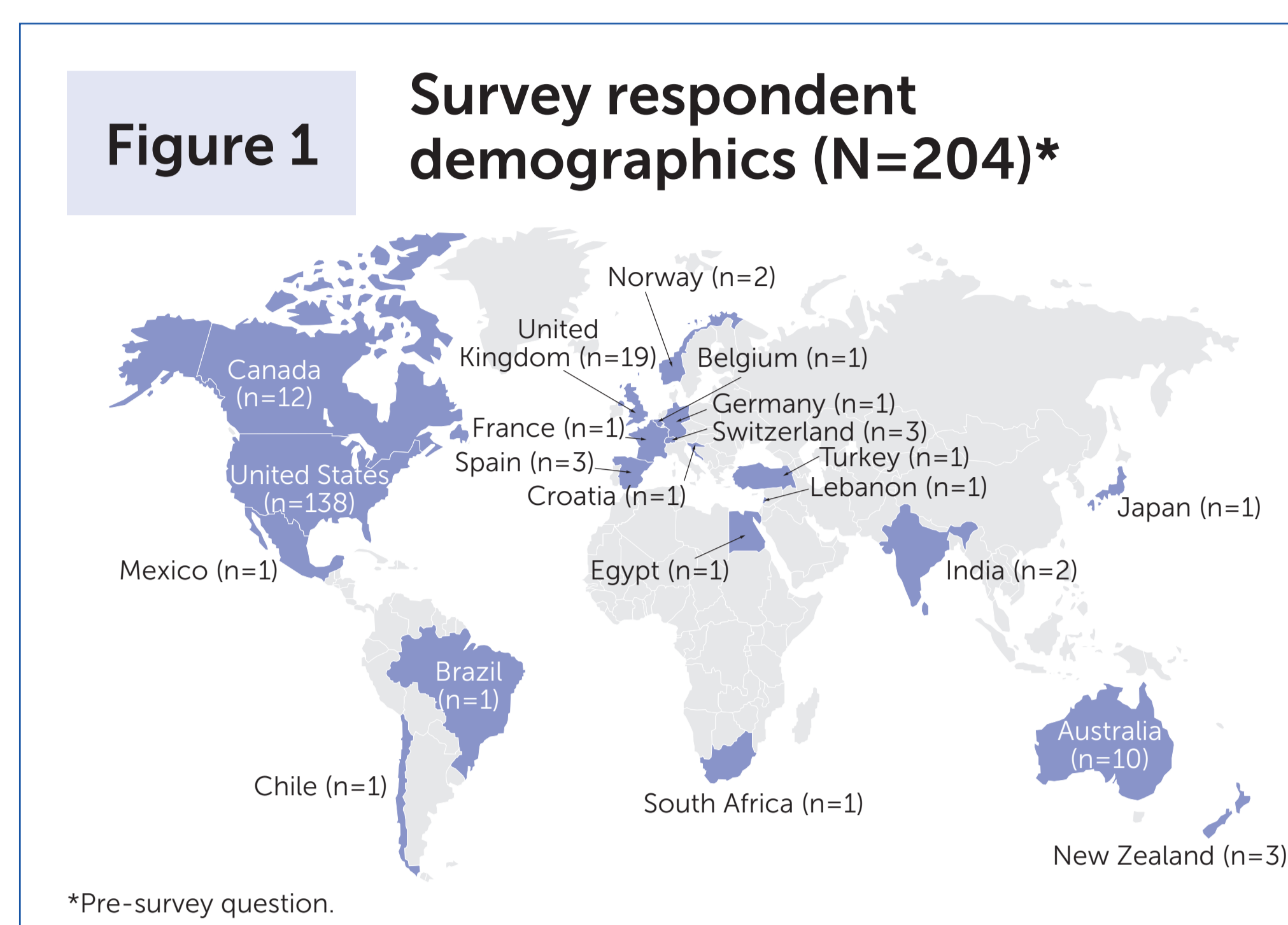
- The most frequently reported first health problem and the MOGAD-related health problem that led respondents to seek medical support were headache (**Figure 3**) and visual disturbance (**Figure 4**)
- 81% of respondents (165/204) sought medical advice within 2 months of experiencing symptoms
 - 8% of patients (16/204) waited >1 year before seeking medical advice

Pathway from initial consultation to MOGAD diagnosis

- For many patients in the United States (**Figure 5**) and Europe, Australia and New Zealand (**Figure 6**), diagnosis occurred following assessment by multiple prior doctors
 - 24% of respondents (48/204) saw five or more doctors before diagnosis (median=4.0)
- For 18% of respondents (36/204) the time taken from first symptom onset to diagnosis was ≥5 years
- 55% of respondents (113/204) reported receiving an alternative primary diagnosis before final MOGAD diagnosis (**Figure 7**)
 - The most common primary alternative diagnosis received was multiple sclerosis (33%, 37/113) followed by neuromyelitis optica (12%, 13/113) and acute disseminated encephalomyelitis (9%, 10/113)
- 60% of respondents (123/204) felt they were not given sufficient information and/or resources at the time of diagnosis

Abbreviations: Ig, immunoglobulin; MOG, myelin oligodendrocyte glycoprotein; MOGAD, MOG antibody-associated disease.

References: 1. Johns TG, Bernard CC. The structure and function of myelin oligodendrocyte glycoprotein. *J Neurochem*. 1999;72(1):1–9. 2. Reindl M, Waters P. Myelin oligodendrocyte glycoprotein antibodies in neurological disease. *Nat Rev Neurol*. 2019;15(2):89–102. 3. Zamvil SS, Slavin AJ. Does MOG Ig-positive AQP4-seronegative opticospinal inflammatory disease justify a diagnosis of NMO spectrum disorder? *Neurol Neuroimmunol Neuroinflamm*. 2015;2(1):e62. 4. QuestionPro. <https://www.questionpro.com/>. Accessed January 2022. **Author disclosures:** Jonathan D. Santoro receives compensation from UCB Pharma on the topic of MOGAD. Jennifer Gould is a Consultant for UCB Pharma and is on the Executive Board of The MOG Project. Zoya Panahloo is an employee and shareholder of UCB Pharma. Ella Thompson was an employee of Cogent working for UCB Pharma on a contract basis at the time of the study. Julia Lefelar is Executive Director and Co-Founder of The MOG Project. Jacqueline Palace has received support for scientific meetings and honoraria for advisory work from Merck Serono, Novartis, Chugai, Alexion, Roche, Medimmune, Argenx, Sanofi, UCB Pharma, Mitsubishi, Amplo Biotechnology and Janssen. She has received grants from Alexion, Roche, Medimmune and Amplo Biotechnology. She holds patent ref. P37347WO and licence agreement with numares multi-marker MS diagnostics; she has shares in AstraZeneca. Acknowledges partial funding by highly specialised services NHS England. **Acknowledgements:** This study was funded by UCB Pharma. The authors acknowledge Rosalind Carney and Niall Harrison of Ogilvy Health, London, UK, for editorial assistance, which was funded by UCB Pharma. The authors acknowledge Veronica Porkess, PhD, of UCB Pharma, Slough, UK, for publication coordination. The authors thank the patients and their caregivers who contributed to this study.



Conclusions

- This survey provides for the first time patients' and caregivers' perspectives from the time of first symptoms to final MOGAD diagnosis
- Approximately 1 in 5 patients reported taking 5 years or more to receive a diagnosis; MOGAD was only recently recognised as a distinct disease, which may account for some delays in diagnosis
- Approximately 1 in 4 patients reported seeing more than five doctors before receiving a final MOGAD diagnosis. This finding could be in part owing to the lack of awareness of MOGAD among non-specialist healthcare professionals and/or non-availability of diagnostic testing for MOG-Ig at that time
- There remains a need to understand the regional/country variation in the patient experiences in the pathway to MOGAD diagnosis
- Greater awareness of MOGAD as a distinct rare demyelinating disease and expert recommendations to support disease definition and diagnosis may help to improve and shorten the pathway from first symptoms to MOGAD diagnosis
- Further work is needed to assess the impact of earlier diagnosis on the long-term burden of MOGAD and health-related quality of life from the perspective of patients and caregivers

Patient Survey Questions*



Pre-survey question: Which country are you from?

1. How old were you (or your child) when you first started experiencing symptoms associated with myelin oligodendrocyte glycoprotein antibody-associated disease (MOGAD)? This can be before you were diagnosed by a doctor.

Please add <numeric value 1–99> _____

2. At what age were you (or your child) diagnosed with MOGAD? **Select one response.**

- a. 0–9 years
- b. 10–18 years
- c. 19–29 years
- d. 30–39 years
- e. 40–49 years
- f. 50–59 years
- g. 60–69 years
- h. 70+ years
- i. NA; not formally diagnosed (if selected, respondent was screened out of survey)

3. Thinking back to before you (or your child) were diagnosed with MOGAD, which of the following was the very first health problem you remember experiencing? **Select all appropriate responses.**

- a. Back pain
- b. Blurred vision/loss of vision
- c. Tiredness/fatigue
- d. Eye pain
- e. Cold/flu-type symptoms
- f. Confusion
- g. Difficulty walking
- h. Headache
- i. Leg/arm tingling/loss of sensation
- j. Leg/arm weakness
- k. Memory problems
- l. Seizures
- m. Urinary problems/incontinence
- n. Other pain
- o. Other; please specify _____

4. Thinking back to before you (or your child) were diagnosed with MOGAD, what other MOGAD-related health problems developed after your first health problem of (response from Q3)?

As best as you can recall, in what order did these other health problems occur? ¹<Drop and drag exercise where respondents select and order from the list below.>

- a. Back pain
- b. Blurred vision/loss of vision
- c. Tiredness/fatigue
- d. Eye pain
- e. Cold/flu-type symptoms
- f. Confusion
- g. Difficulty walking
- h. Headache
- i. Leg/arm tingling/loss of sensation
- j. Leg/arm weakness
- k. Memory problems
- l. Seizures
- m. Urinary problems/incontinence
- n. Other pain
- o. Other; please specify _____
- p. I did not have any other health problems

5. What were the main MOGAD-related health problems that eventually made you (or your child) seek medical advice from a healthcare professional? In other words, what were your most severe symptoms that required you to seek medical care? **Select all appropriate responses.**

- a. Back pain
- b. Blurred vision/loss of vision
- c. Tiredness/fatigue
- d. Eye pain
- e. Cold/flu-type symptoms
- f. Confusion
- g. Difficulty walking
- h. Headache
- i. Leg/arm tingling/loss of sensation
- j. Leg/arm weakness
- k. Memory problems
- l. Seizures
- m. Urinary problems/incontinence
- n. Other pain
- o. Other; please specify _____

6. How long did it take between your first MOGAD symptom and seeking medical advice?

- a. Less than 2 months
- b. 2 to 5 months
- c. 6 to 12 months
- d. >1 year; specify number of years _____

7. If the answer to Question 6 = D. Please explain the reason for waiting more than 1 year to seek medical advice.

<open end w/ significant number of characters, e.g. 2000> _____

8. What type of doctor did you (or your child) see when you first sought medical advice for your initial MOGAD health problems?

- a. Primary care doctor (General practitioner/Family Medicine/Internist)
- b. Pediatrician (doctor who treats children)
- c. Ophthalmologist (doctor who treats disorders of the eye)
- d. Neuro-ophthalmologist (doctor who treats disorders of the eye caused by brain disease)
- e. General neurologist (doctor who treats brain disorders)
- f. Neuro-immunologist (doctor who treats brain disorders caused by the immune system)
- g. Movement disorder specialist (doctor who treats brain disorders with muscular issues)
- h. Emergency care doctor
- i. Geneticist (doctor who treats people with genetic disorders)
- j. Other; please specify _____

9. What type of doctor were you (or your child) referred to next?

- a. Primary care doctor (General practitioner/Family Medicine/Internist)
- b. Pediatrician (doctor who treats children)
- c. Ophthalmologist (doctor who treats disorders of the eye)
- d. Neuro-ophthalmologist (doctor who treats disorders of the eye caused by brain disease)
- e. General neurologist (doctor who treats brain disorders)
- f. Neuro-immunologist (doctor who treats brain disorders caused by the immune system)
- g. Movement disorder specialist (doctor who treats brain disorders with muscular issues)
- h. Emergency care doctor
- i. Geneticist (doctor who treats people with genetic disorders)
- j. Other; please specify _____
- k. NA; you (or your child) were not referred to another physician

10. How long did you (or your child) have to wait to see the doctor to which you were referred?

- a. 1 week
- b. 2 to 3 weeks
- c. 4 to 6 weeks
- d. 2 months
- e. 3 months
- f. 4 months
- g. 5 months
- h. 6 months
- i. Longer than 6 months
- j. Other; please specify _____

11. What type of doctor eventually made your (or your child's) diagnosis of MOGAD?

- a. Primary care doctor (General practitioner/Family Medicine/Internist)
- b. Pediatrician (doctor who treats children)
- c. Ophthalmologist (doctor who treats disorders of the eye)
- d. Neuro-ophthalmologist (doctor who treats disorders of the eye caused by brain disease)
- e. General neurologist (doctor who treats brain disorders)
- f. Neuro-immunologist (doctor who treats brain disorders caused by the immune system)
- g. Movement disorder specialist (doctor who treats brain disorders with muscular issues)
- h. Emergency care doctor
- i. Geneticist (doctor who treats people with genetic disorders)
- j. Other; please specify _____

12. How many different doctors did you (or your child) see in total before you finally received your diagnosis of MOGAD?

Please add <numeric value 1–99> _____

13. From the time that you (or your child) first experienced health issues related to MOGAD, how long did it take to get diagnosed?

- a. Less than 6 months
- b. 6 to 11 months
- c. 1 year
- d. 2 years
- e. 3 years
- f. 4 years
- g. 5 years
- h. 6 years
- i. 7 years or more

14. If the answer to Question 13 = I. Please explain why it took 7 years or more to get a MOGAD diagnosis from the point of your initial symptoms.

15. From the time that you (or your child) saw the very first doctor for your initial health problems, how long did it take to get diagnosed with MOGAD?

- a. Less than 6 months
- b. 6 to 11 months
- c. 1 year
- d. 2 years
- e. 3 years
- f. 4 years
- g. 5 years
- h. 6 years
- i. 7 years or more

16. If the answer to Question 15 = I. Please explain why it took 7 years or more to get a MOGAD diagnosis from the point of when you saw your first doctor.

17. Thinking back to before you (or your child) had the diagnosis of MOGAD, were you (or your child) misdiagnosed with another illness?

- a. Yes; please specify other medical diagnoses: _____
- b. No
- c. I don't remember

18. Do you feel you (or your child) were provided with enough information and/or resources at the time of your (or your child's) MOGAD diagnosis?

- a. Yes
- b. No

19. If the answer to Question 18 = B. What information and/or resources would you have liked to receive at the time of your MOGAD diagnosis?

- a. Pamphlets
- b. Brochure
- c. Online video resources
- d. Advocacy website information
- e. Support group information
- f. Other; please specify _____
<open end w/ significant number of characters, e.g. 2000>

20. Which type of doctor do you currently see for the management of your MOGAD?

- a. Primary care doctor (General practitioner/Family Medicine/Internist)
- b. Pediatrician (doctor who treats children)
- c. Ophthalmologist (doctor who treats disorders of the eye)
- d. Neuro-ophthalmologist (doctor who treats disorders of the eye caused by brain disease)
- e. General neurologist (doctor who treats brain disorders)
- f. Neuro-immunologist (doctor who treats brain disorders caused by the immune system)
- g. Movement disorder specialist (doctor who treats brain disorders with muscular issues)
- h. Emergency care doctor
- i. Geneticist (doctor who treats people with genetic disorders)
- j. Other; please specify _____

21. Please share any thoughts you have about your 'journey' from first experiencing health issues related to MOGAD, to when you were finally diagnosed with MOGAD. Please include your thoughts about the importance or the value that you give to having a proper and timely diagnosis and how the diagnostic process could be improved.

<open end w/ significant number of characters, e.g. 2000> _____

22. Prior to your (or your child's) MOGAD diagnosis, if any, what sort of activities were you unable to perform because of your (or your child's) health problems related to MOGAD? How did having a final MOGAD diagnosis change anything?

<open end w/ significant number of characters, e.g. 2000> _____

23. Have you (or your child) had any long-term health consequences as a result of not being diagnosed earlier with MOGAD? Please provide details.

<open end w/ significant number of characters, e.g. 2000> _____

*Response options were presented in a random order for all multiple-choice questions.

¹Questions 3 and 4 were presented as one question; respondents were asked to place health problems in the order in which they occurred, starting with the first health problem experienced.