Macular Degeneration Foundation™

Our focus is your vision

Project Vision II: The Macular Degeneration Foundation Members Survey

Macular Degeneration Foundation

July 2008

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Executive Summary

Macular Degeneration (MD) is the leading cause of blindness in Australia, currently affecting 1 in 7 over the age of 50 in Australia. The Macular Degeneration Foundation is a national peak body committed to working on behalf of the MD community, especially those with the disease, their families and carers. The key aim of the MD Foundation is to reduce the incidence and impact of MD in Australia. This is achieved through education, awareness, support services, research and representation.

The aim of this report is to present the findings of the MD Foundation's recent research project titled *'Project Vision 2'*, which commenced in February 2007and was completed in February 2008. The ultimate objective of the research project is to ascertain the experiences, the needs and the extent of knowledge about the disease amongst members of the MD Foundation. These objectives were achieved by focusing on four key areas:

- Diagnosis and awareness of the disease
- Management and monitoring of the disease
- Access and use of low vision services and low vision aids
- Evaluation of The Macular Degeneration Foundation's services

In gaining a clearer understanding of the experiences of the MD community in Australia, the Foundation aims to use the findings of this study to identify areas which the Foundation can better assist those affected by MD, their families and carers.

A cross-sectional survey was designed to address the research objectives of this study and mailed out to over 5,000 people, randomly selected from the MD Foundation database. A total of 2010 people responded (a response rate of 37%).

The study identified a number of areas which require serious consideration. For instance, the results suggested that 50% of those who have MD either did not have access to low vision services or did not know how to access such services. The study results also found that a vast majority of those with MD (81%) reported experiencing frustration due to their vision impairment. Furthermore, over a third (37%) of those with MD reported to have experienced phantom images. This is an aspect of the disease that requires a focus on education and awareness with the MD community and also with the health care professionals.

The study also demonstrates that the vast majority of those who use the Foundation's services are highly satisfied with the services provided by the Foundation.

The results of this study will guide the Foundation's future education program and awareness campaigns, with a comprehensive strategic communication plan. The results will also be used to guide the design of '*Project Vision 3'*.

Introduction

Macular Degeneration (MD) is the term used to describe the disease of the macula, which is the central part of the retina that lines the back of the eye. The macula is responsible for central vision; which enables a person to see fine detail and colour, and is necessary for carrying out daily tasks such as reading, driving and recognising faces[1]. The deterioration of the macula results in the progressive, permanent loss of central vision.

MD is the leading cause of blindness and severe vision loss in Australia. Although MD can affect younger people it is most often related to ageing, as its incidence increases dramatically with age. It is therefore often referred to as Age-related Macular Degeneration (AMD).

MD is the primary cause of visual impairment in Western developed countries and the third most common cause of blindness worldwide[2]. In Australia, MD is responsible for 48% of severe vision loss[3]. It is estimated that MD affects 1 in 7 people over the age of 50, with incidence increasing with age[4]. The high incidence of Macular Degeneration amongst older Australians has important ramifications for Australia. Currently 25% of the population is over the age of 55[5], and according to Department of Health and Ageing the current baby boomers numbers will increase the over 65 age group by 50% over the next 10 -15 years[6]. Within the context of an ageing population and the likelihood of an increase in the incidence and prevalence of MD as the population ages, MD is fast emerging as a serious public health problem. It is estimated that MD costs Australians AUS $2.6 billion a year and over the next 20 years, the cost to the community will be $59 billion[7]. Currently MD is incurable and in many cases untreatable. MD is a disease which affects a persons' physical, emotional, economical and social well being, reducing their quality of life and level of independence.

The Macular Degeneration Foundation is a national peak body committed to working on behalf of the MD community, especially those with the disease, their families and carers. The key aim of the MD Foundation is to reduce the incidence and impact of MD in Australia. This is achieved through education, awareness, support services, representation and research.

Research is a key objective of the MD Foundation. '*Project Vision 2'* plays an integral part in helping the Foundation meet its commitment to the Australian MD Community.

The aim of this report is to present the findings of the MD Foundation's recent research project titled *'Project Vision 2'*, which commenced in February 2007and was completed in February 2008. The ultimate objective of the research project is to ascertain the experiences,

the needs and the extent of knowledge about the disease amongst the members of the MD Foundation. These objectives were achieved by focusing on four key areas:

- Diagnosis and awareness of the disease
- Management and monitoring of the disease
- Access and use of low vision services and low vision aids
- Evaluation of The Macular Degeneration Foundation's services

A cross-sectional survey was designed to address the research objectives of this study and mailed out to over 5,000 people, who were randomly selected from the MD Foundation database.

Research Aims

A number of research questions have been formulated in relation to each of the four focus areas, and are as follows:

Diagnosis and awareness of the disease

- What are the experiences of people with MD at the diagnostic stage?
- What is the extent of knowledge of MD amongst the MD Community?

Management and monitoring of MD

- What are people with MD doing to manage their condition?
- How frequently are people with MD monitored and by whom?

Access and use of low vision services and low vision aids

- To what extent are people with MD utilising the various low vision aids and low vision services available in Australia?

Evaluation of the Macular Degeneration Foundations' Services

- Are the services provided by the Foundation meeting the needs of the MD community in Australia?

These specific research questions were formulated with the aim to gain a clearer understanding of the experiences of the MD community in Australia. By presenting the findings, this report will enable the MD Foundation to identify areas which the Foundation may be able to better assist those affected by MD, their families and carers.

Method

A cross-sectional survey was designed to address the research objective of this study. The cross-sectional survey method was chosen as it is the most appropriate research method to obtain descriptive data to ascertain the experiences, behaviour, expectations and opinions of participants in the study.

Materials

A self administered questionnaire was designed for people on the MD Foundation's database. An information letter was sent out with the questionnaire, explaining the study, requesting voluntary participation and guarantying confidentiality and anonymity. A reply paid envelope was included and participants were asked to complete the questionnaire and return it to the Foundation or telephone the researcher if they required assistance in completing the survey over the phone. Both the questionnaire and the information letter were in large print (type Arial font, size 14 bold).

The questionnaire was developed in consultation with the MD Foundation's Medical Committee, Client Services Committee and Professor Paul Mitchell (the Foundation's National Research Advisor). The questionnaire consisted of a series of questions intended to establish what people on the MD Foundations' database:

- Understood about MD,
- The means of slowing down the progression of the disease or reducing their risk,
- The source of their information,
- Their experiences with their eye care professionals at diagnostic stage, and monitoring stage,
- Their use and/ or knowledge of low vision aids and /or services available, and
- Demographic information such as gender, age, and ethnicity was also obtained.

The questionnaire obtained both quantitative and qualitative data, using a combination of both closed and open-ended questions. Filter questions were included for a number of questions. Five people from the MD Foundation's database were asked to pilot the questionnaire. Four pilot questionnaires were self administrated and one was conducted on the phone, with the researcher. Two people that participated in the pilot had Wet MD, two people had Dry MD and one did not have MD but knew someone with MD. Upon studying the responses the layout of the questionnaire was altered and a question regarding feelings of frustration due to visual impairment was added.

Sample

Two stratified random samples were taken from the MD Foundation's database; one sample of 3,500 was taken on the 29th January 2007, during which time there were approximately 15,000 members and another sample of 2,000 was taken 7th November 2007, when the number of people on the Foundation's database was approximately 19,000. The majority of people on the MD Foundation's database are over the age of 55 and either has developed MD, has a family member or friend with MD or care for someone with MD.

A stratified random sample was used in an effort to reduce sampling bias. The sample was stratified according to the percentage of Australians over the age of 55 in each State or Territory (see table 1).

Table 1: Sample Stratified according to 55 year olds in each State

	ACT	NSW	NT	QLD	SA	TAS	VIC	WA
% of over 55 year olds in each state*	1.5%	33%	0.6%	19%	8%	3%	25%	9%
% of respondents in each state	1.5%	34%	0.5%	19%	9.5%	3%	24%	9%
No. of respondents in each state	31	679	9	376	193	53	487	182

*The total number of people over the age of 55 in Australia is 5'091,356
Population estimate as of the 30th June 2007 - Source ABS cat no. 3101.0

From the total of 5,500 people randomly selected from the Foundation's database, a total of 2010 people responded (a response rate of 37%). Sixty nine respondents completed the questionnaire over the phone with the researcher and 1941 respondents mailed the back the questionnaire. The questionnaires were mailed out throughout 2007, commencing in February 2007 and concluding in February 2008.

Data integrity

As the questionnaires were self-completed and machine-read, not all questions have complete data from all respondents.
Any discrepancies are noted on the charts.

Research Participants

A total of 2010 participants responded. The participant's demographic characteristics are outlined in table 1. Seventy per cent of the participants were female and 40% were in the 75-84 years age group. The average age of the Foundation's members is 73.81 years. For the vast majority, 94%, their first language is English and 23% were born overseas, the majority of which were born in English speaking countries. A large majority, 78%, of the respondents have MD and a further 11% have a family member with MD. Forty six percent who reported having MD were in the 75-84 years age group. As this study did not include a visual acuity test for the participants, participants were asked about their driving ability as a means to ascertain the level of visual impairment amongst the participants. Thirty five percent of participants reported that their driving ability was somehow affected by MD, 26% of which reported that they could no longer drive due to MD.

Table 2: Participants' Characteristics

Participants	Frequencies	Percentage*
Gender		
Female	1402	70
Male	597	30
Age		
Under 54	129	6
55-64	261	13
65-74	499	25
75-84	795	40
85-94	303	15
95+	16	1
Born Overseas		
Yes	461	23
No	1544	77
English First Language		
Yes	1880	94
No	126	6
Have MD		
Yes	1560	78
Family member with MD	216	11
Care for someone with MD	31	2
Friend with MD	59	3
General Interest	124	6
Driving Ability		
No longer drive due to MD	404	26
Driving ability limited due to MD	114	7
Restricted license due to MD	28	2

n = 2003 *Percentages might not add up due to rounding

Findings

The main objective of this study was to ascertain the experiences, behaviour, expectations and opinions of participants in the study. This was achieved by focusing on four key areas which are central to gaining a clear insight into Macular Degeneration in Australia. As such the findings have been divided into four sections addressing each of the focus areas:

- Awareness and Diagnosis of MD.
- Management and monitoring of the disease.
- Access and use of low vision services and low vision aids.
- Evaluation of the Macular Degeneration Foundation services.

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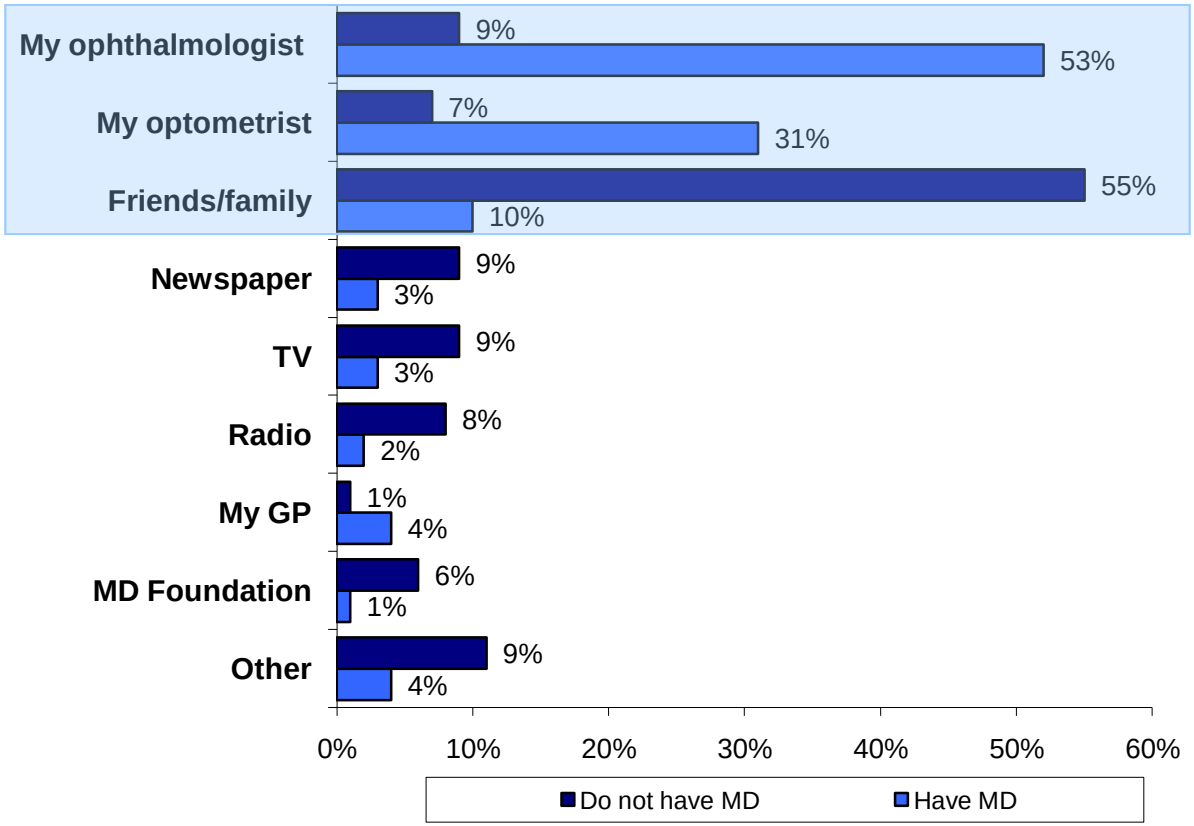
Awareness and diagnosis of MD

Where did you first hear about MD?

- The Foundation members usually learn about MD through personal contact, although their sources vary between those who have MD and those who do not.
- Those with MD mainly learn about MD from their ophthalmologists (53%) and optometrists (31%).
- Those who do not have MD usually learn about the complaint from family and friends (55%).

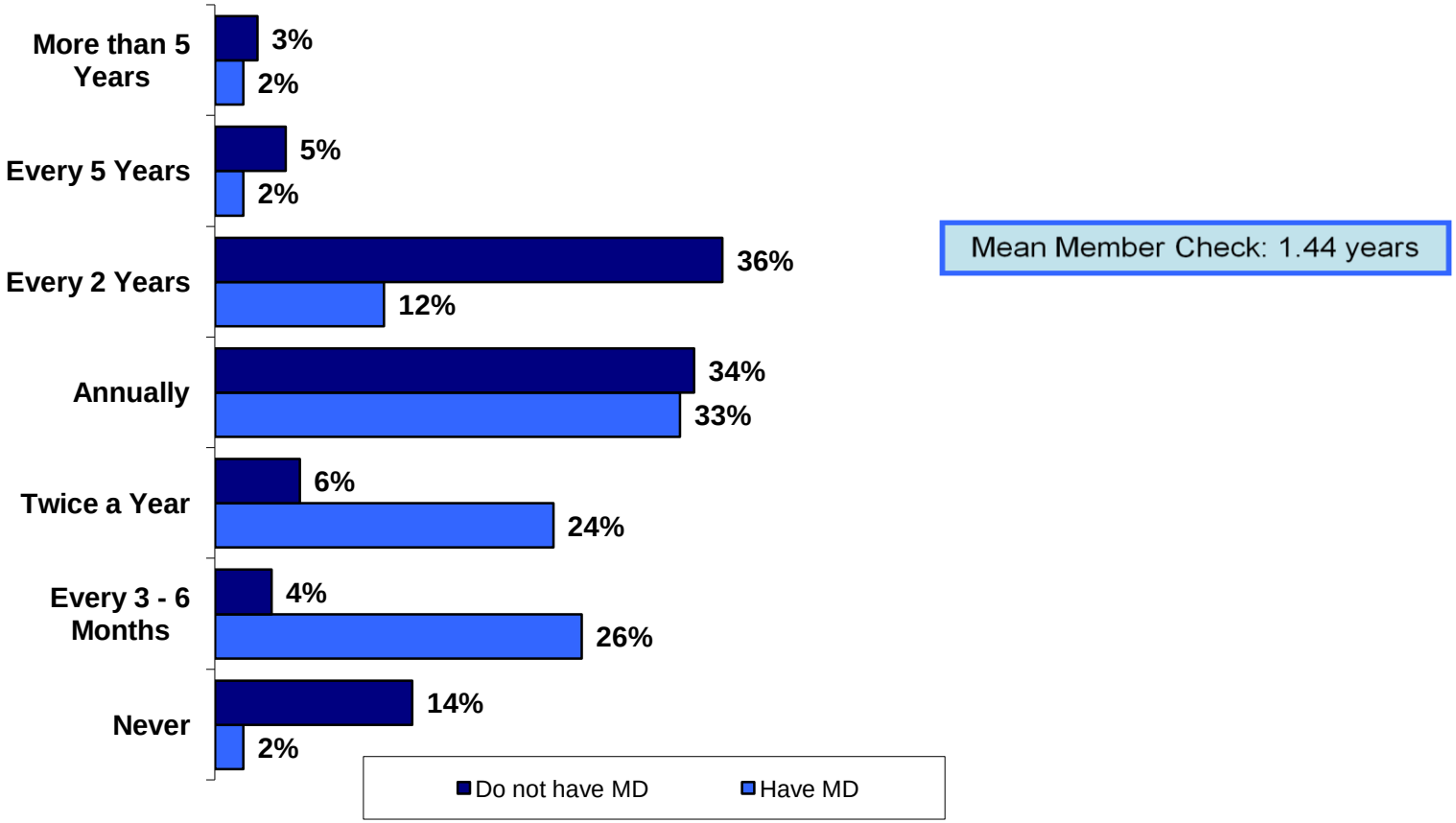


Base n=2010, all respondents (3% didn't answer)

Multiple responses possible

MD check frequency

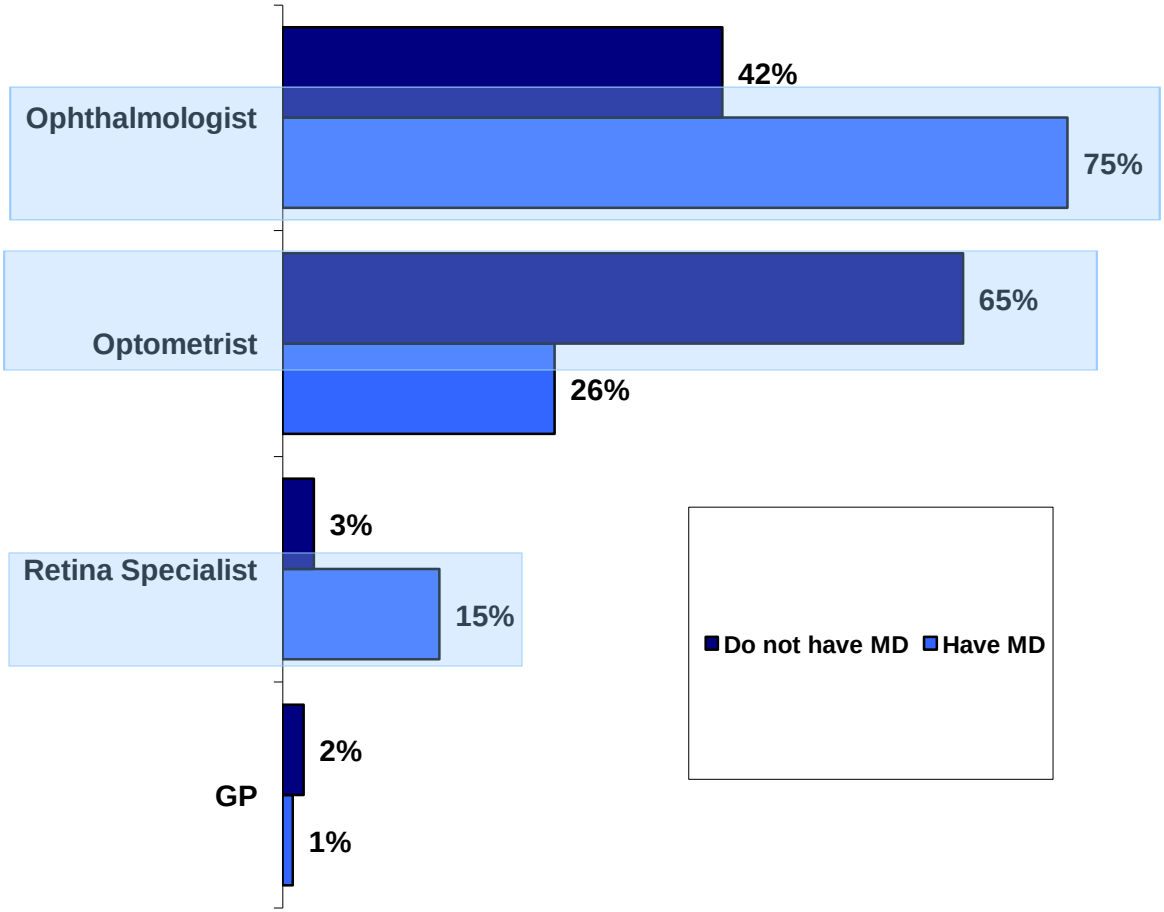
- Overall 74% of the Foundation members have their eyes checked for MD at least once a year. 41% are tested at least twice a year. However, there is considerable variation in frequency between those with MD and those without MD.
- Amongst those with MD, 83% have a vision check at least annually, 50% at least twice a year.
- Amongst those who do not have MD 44% have at least an annual check, 10% has a check at least twice a year.
- A further 14% undergoes no checks.



Base n=2010, all respondents (3% didn't answer)

Type of professional visited for MD check

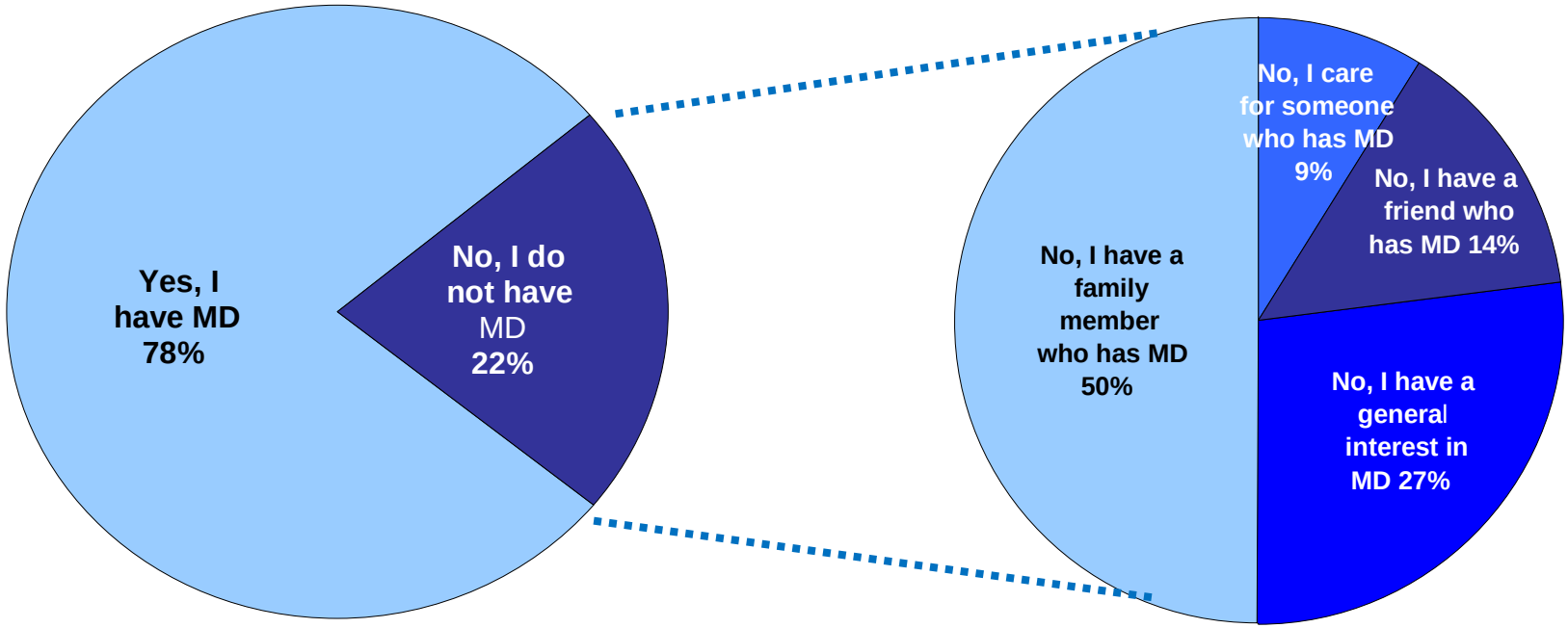
- Those with MD predominantly have their eyes checked by an eye specialist, (90%) go to an ophthalmologist, and in 15% of cases their ophthalmologist was a retina specialist.
- Those without MD, however, are less likely to visit a specialist. Instead, 65% go to an optometrist.



Base n=1910, respondents who have their eyes checked

Do you have MD?

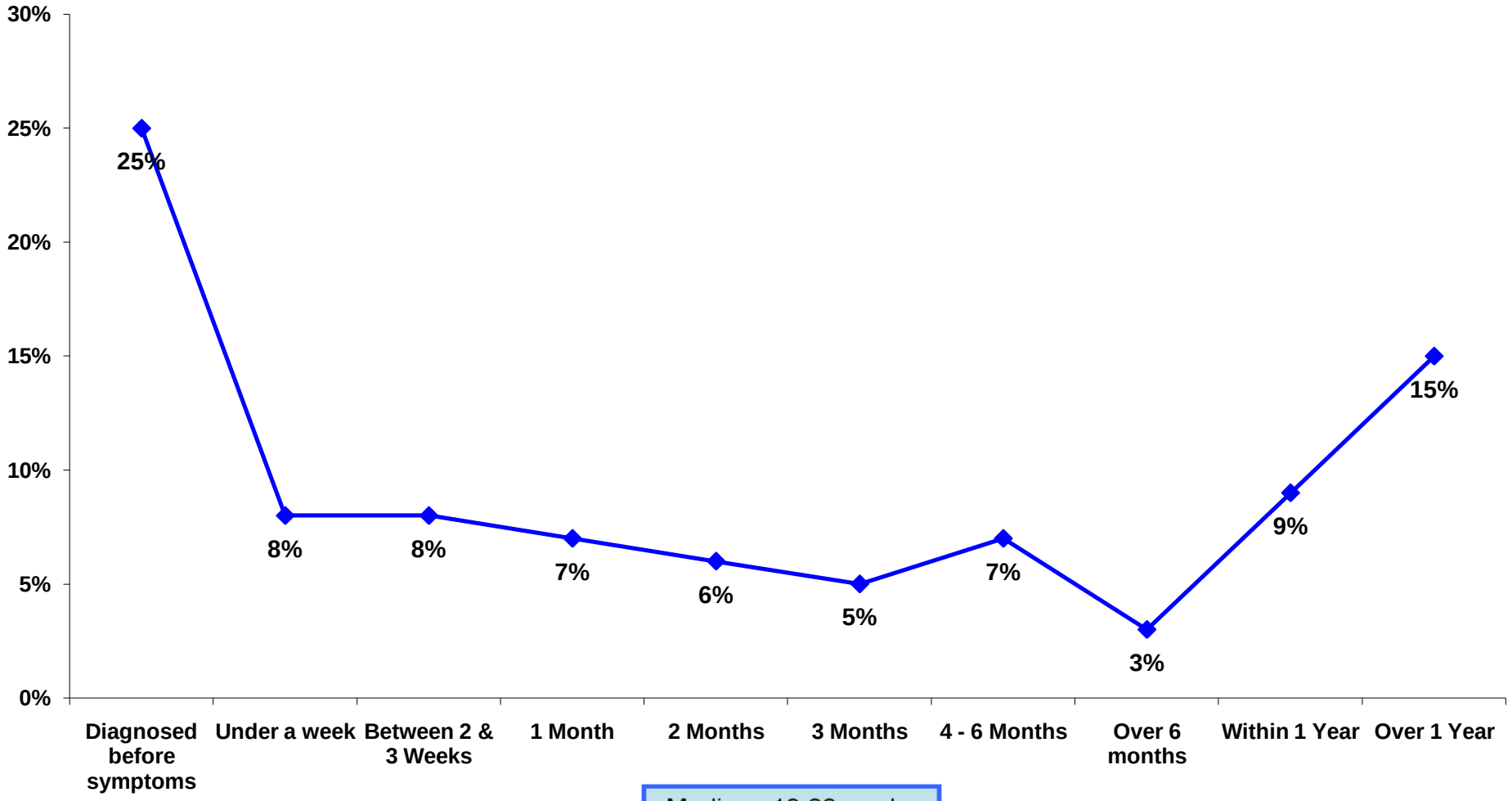
- 78% Foundation members have MD.
- Of those who do not have MD, half (50%) have a family member with MD.



Base n=2010, all respondents

Length of diagnosis period

- The median time from the appearance of symptoms to diagnosis is 13.88 weeks.
- 25% of members with MD were diagnosed before the symptoms appear.

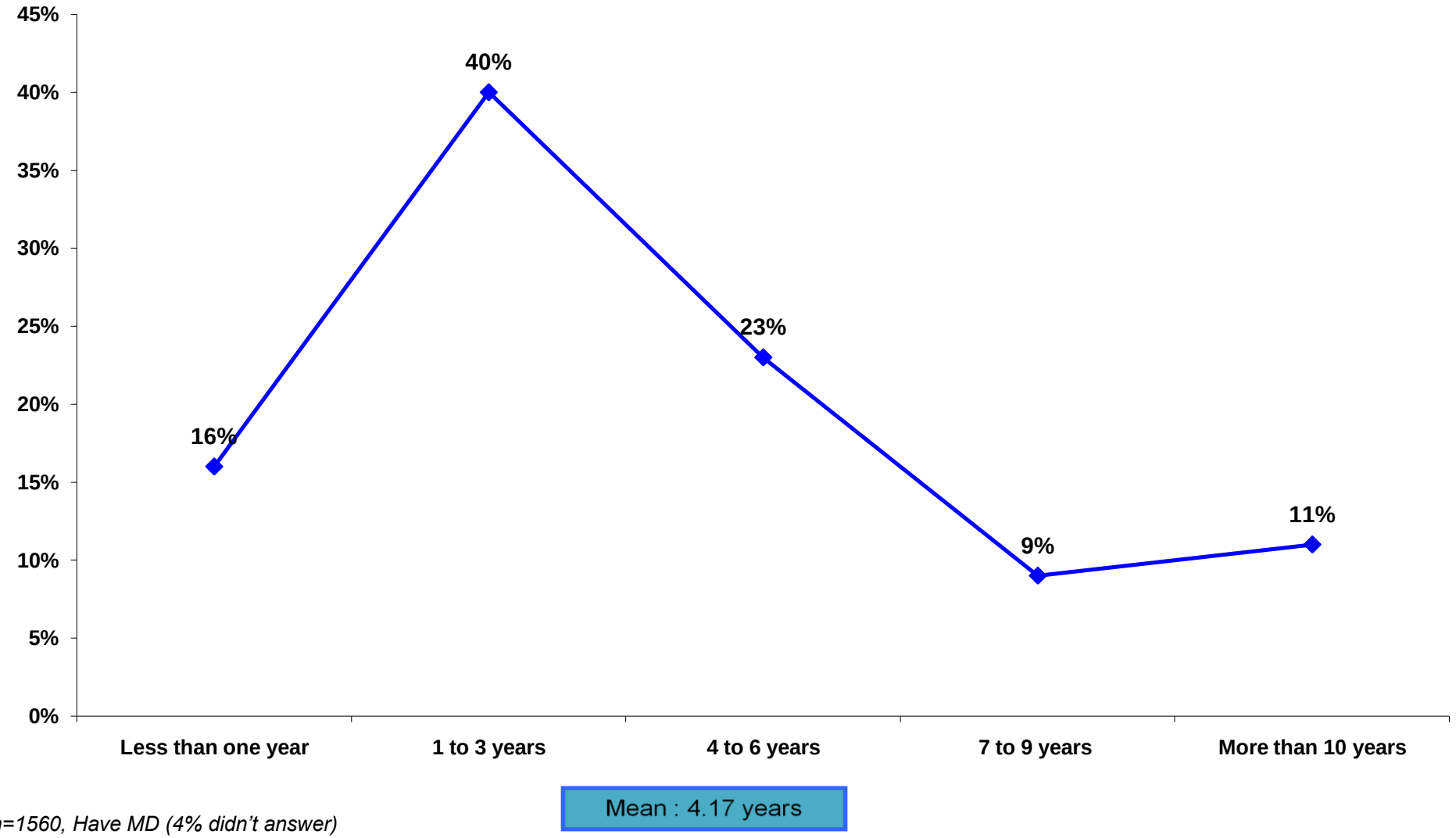


Median : 13.88 weeks

Base n=1560 Have MD (11% didn't answer)

How long ago MD was diagnosed

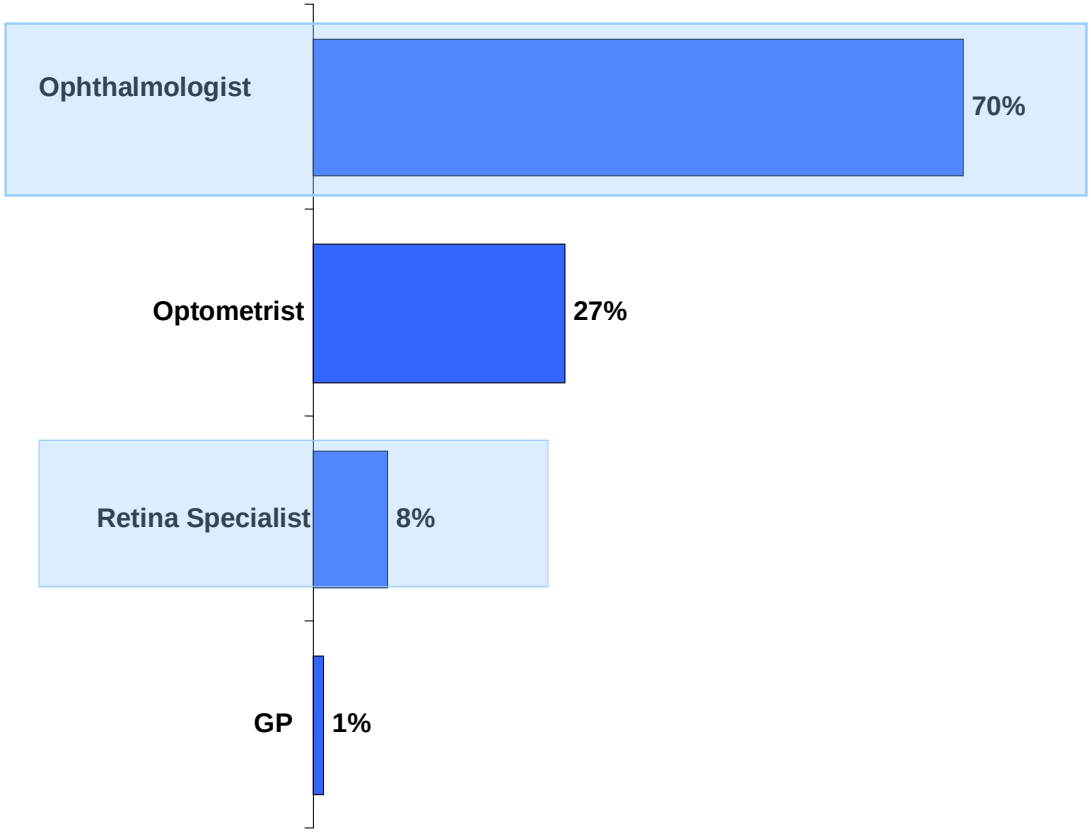
- On average, members who have MD were diagnosed with the condition just over four years previously.



Base n=1560, Have MD (4% didn't answer)

Who diagnosed MD?

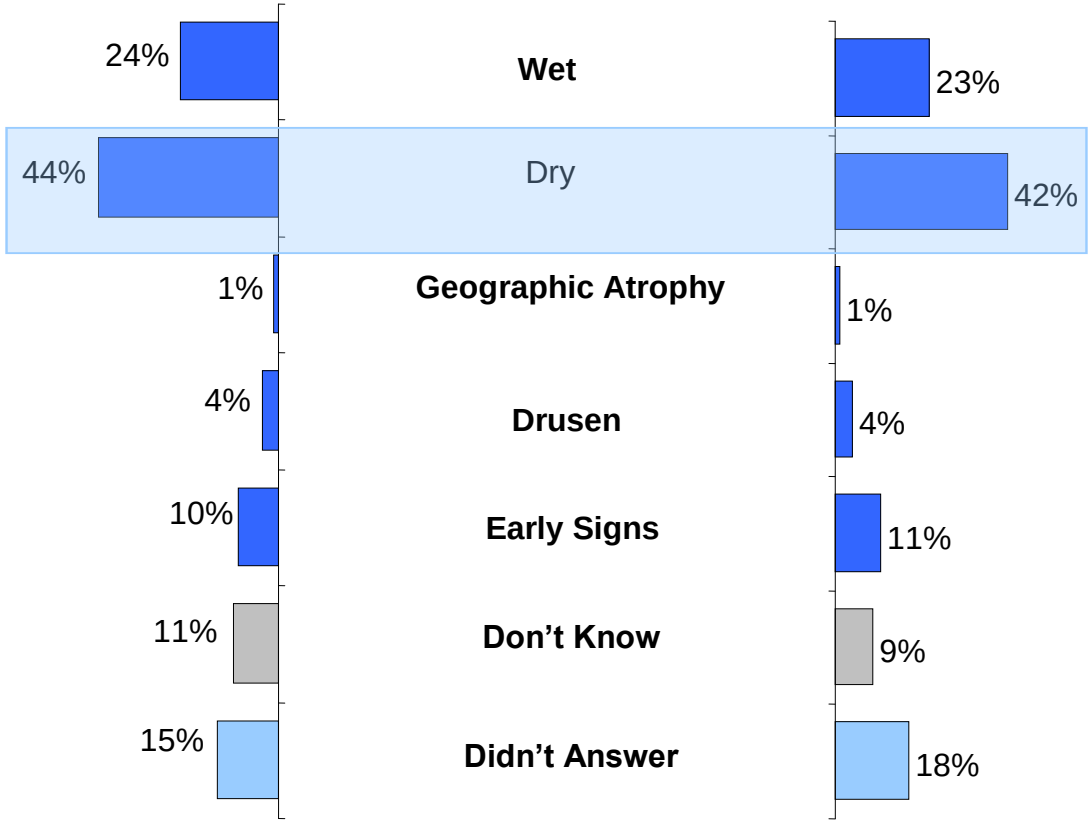
- In the majority of cases, (78%), MD is diagnosed by an eye specialist and in 8% of cases their ophthalmologist was a retina specialist.
- Only 1% of participants were diagnosed by their GP.



Base n=1560, Have MD (4% didn't answer)

Type of MD by eye

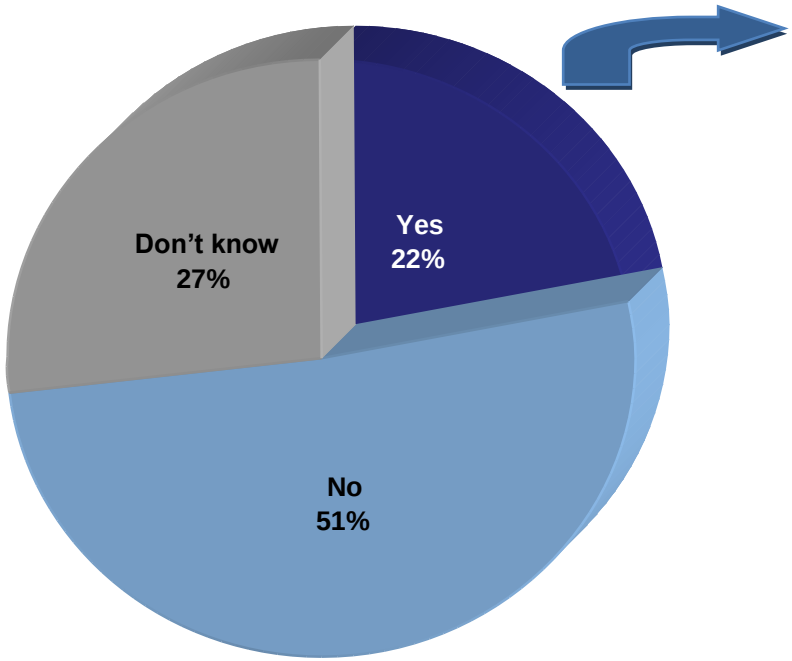
- Participants were asked to indicate what type of MD they had; their response appears to suggest that MD appears to be equally distributed between both eyes.
- The Participants' response also appears to suggest that the most common form of MD is 'Dry' (Left eye: 44%, Right eye: 42%)
- A number of respondents gave multiple conflicting responses, suggesting that participants are confused about the type of MD they have.

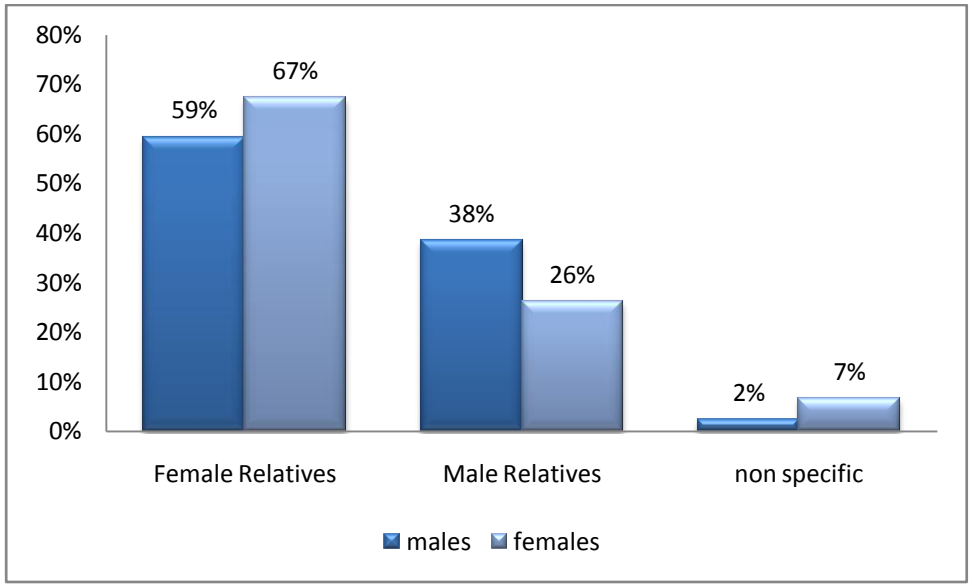


Base n=1560, Have MD

Family history of MD

- 22% members with MD have a family history of the disease.
- 27% of members who have MD do not know whether they have a family history of MD.
- Of those who reported having a family history of MD, Females appear to have more female relatives with the disease.

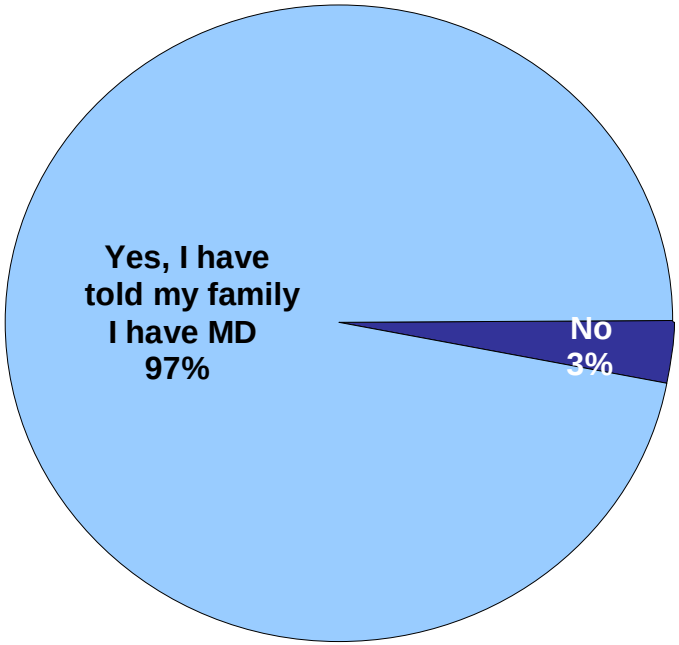




Base n=1560, Have MD (2% didn't answer)

Telling the family about MD diagnosis

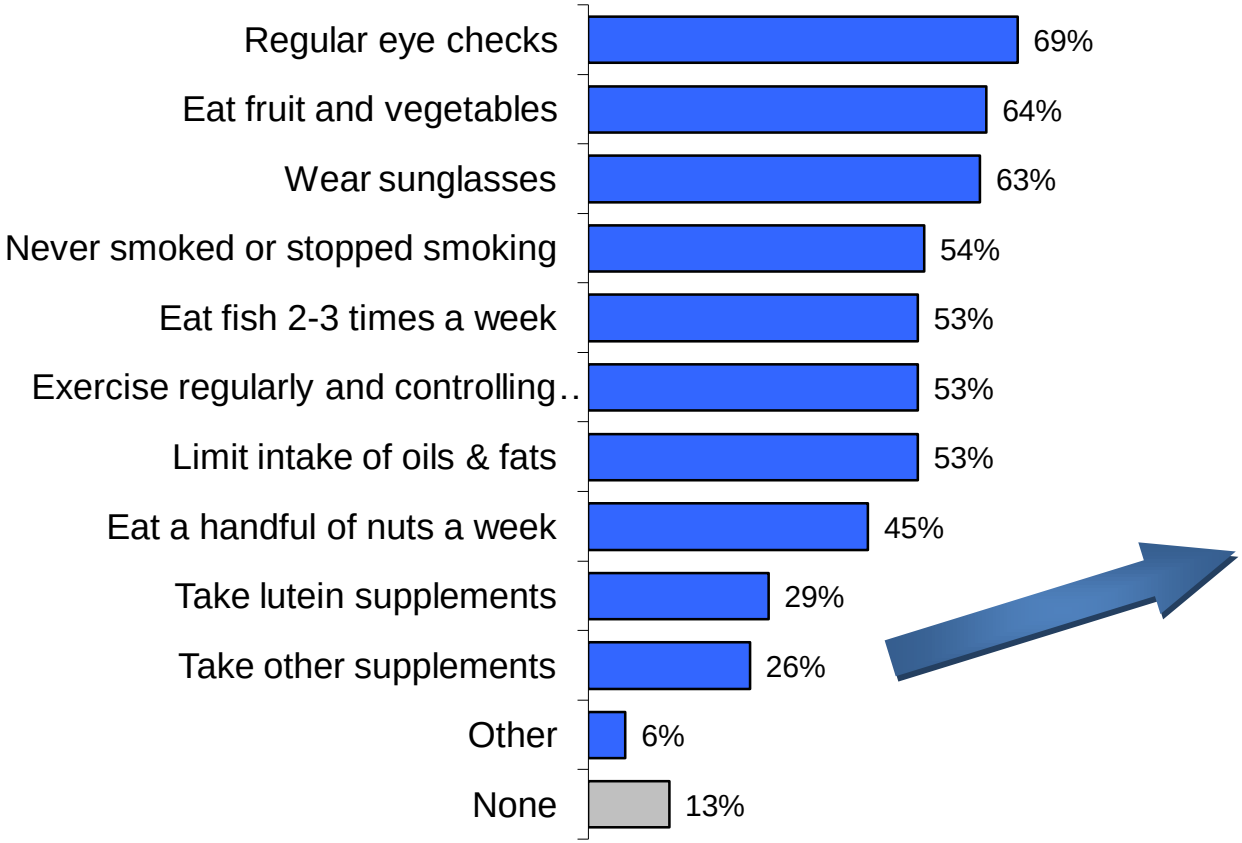
- Awareness of the patient's condition amongst their families is almost universal (97%).



Base: n=1560 Have MD (2% didn't answer)

Telling the family about risk reduction steps

- Those with MD encourage family members to have regular eye checks, improve their diet, wear sunglasses and stop smoking.
- 29% encourage family members to take Lutein supplements, while only 26% encourage family members to take other supplements.



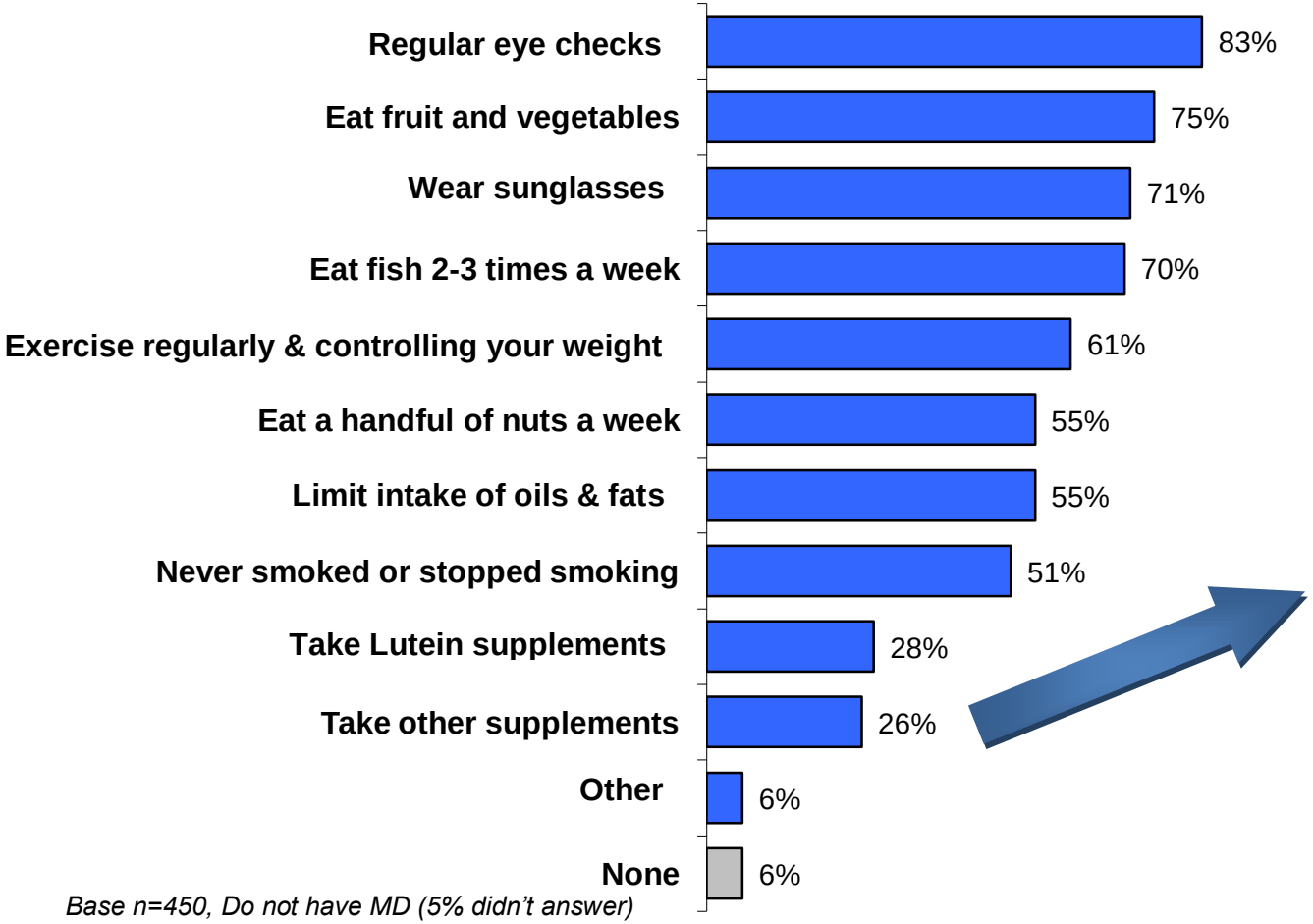
Other Supplements (n=199)	
AREDS Formula	70%
Other Eye Supplements	19%
Other Supplements	7%
Multi-Eye Supplements	3%
Non-Specific or Confused	3%

Base n=1560, Have MD (11% didn't answer)

Multiple responses possible

Awareness of MD risk reduction practices amongst those who do not have MD

- Those who do not have MD are more aware of regular eye checks, changes in diet and wearing sunglasses as preventative measures.
- They are less likely to mention weight control, exercise or supplements.



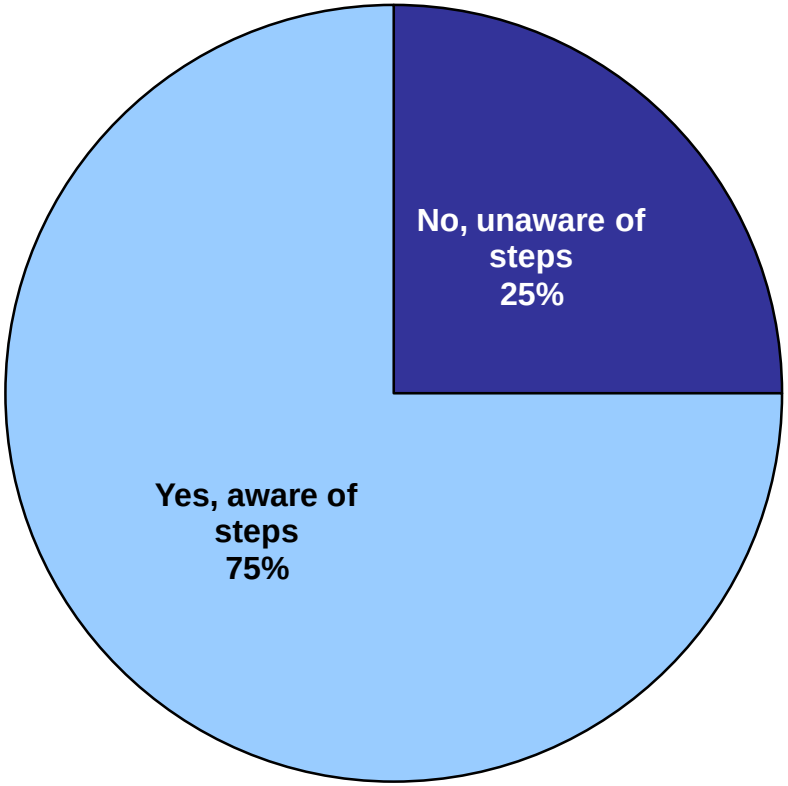
Base n=450, Do not have MD (5% didn't answer)

Other Supplements (n=107)	
AREDS Formula	53%
Other Eye Supplements	22%
Other Supplements	14%
Non-Specific or Confused	10%
Multi-Eye Supplements	1%

Multiple responses possible

Awareness of steps for slowing down the progression of MD

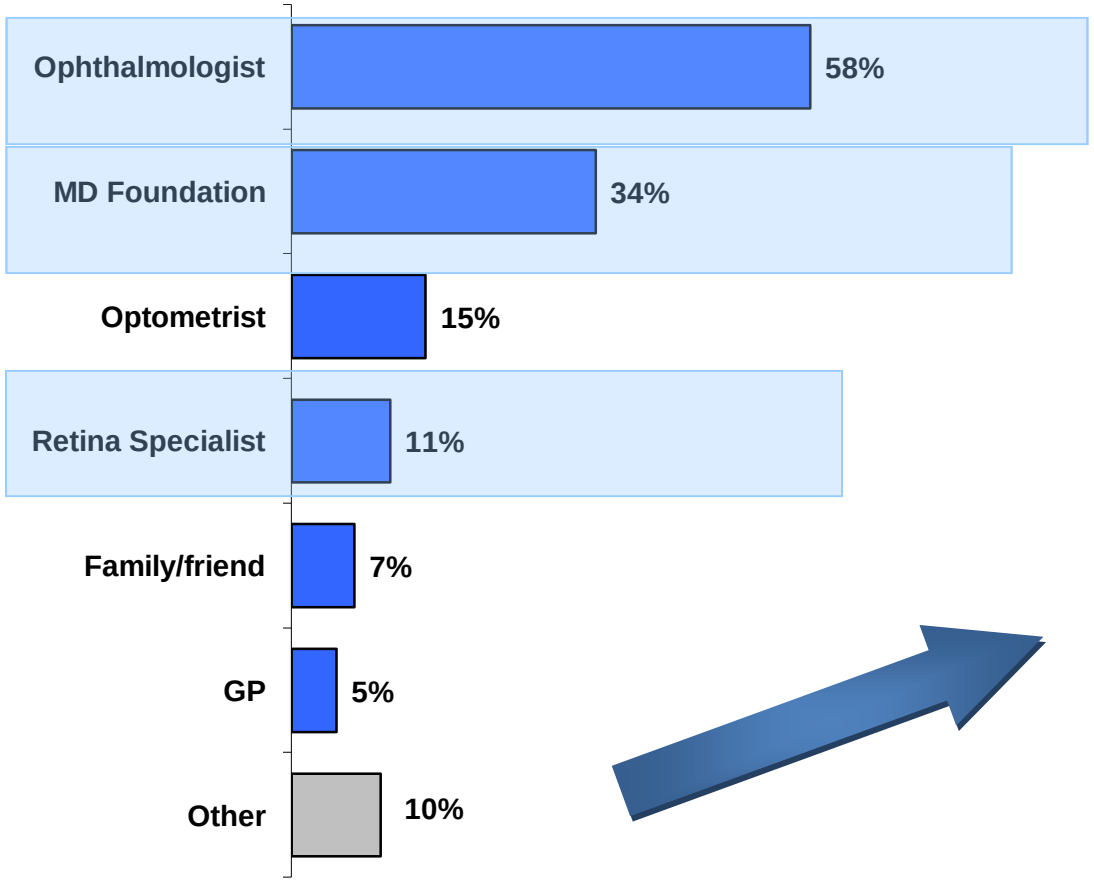
- 25% of those who have MD are not aware of steps they can take to slow progression of the disease.



Base n=1560, Have MD (7% didn't answer)

Source of information on steps to slow MD progression

- 69% of those with MD who are aware of the steps they can take to slow the progress of the disease were given this information by their ophthalmologist and in 11% of cases their ophthalmologist was a retina specialist.
- 34% of members who have MD obtained their information from the Foundation.



Other (n=125)	
No one	**32%**
Literature	**24%**
Low Vision Org	**9%**
Internet	**8%**
MDF	**8%**
Various media	**6%**
Naturopath	**6%**
Health food shop	**4%**
Pharmacist	**2%**
Support Group	**2%**
HCP	**1%**

Base n=1075, Have MD and are aware of steps to slow MD progression

Multiple responses possible

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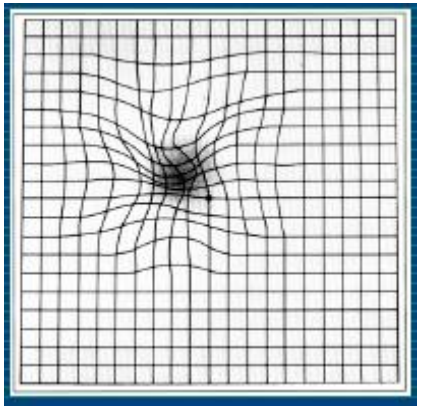
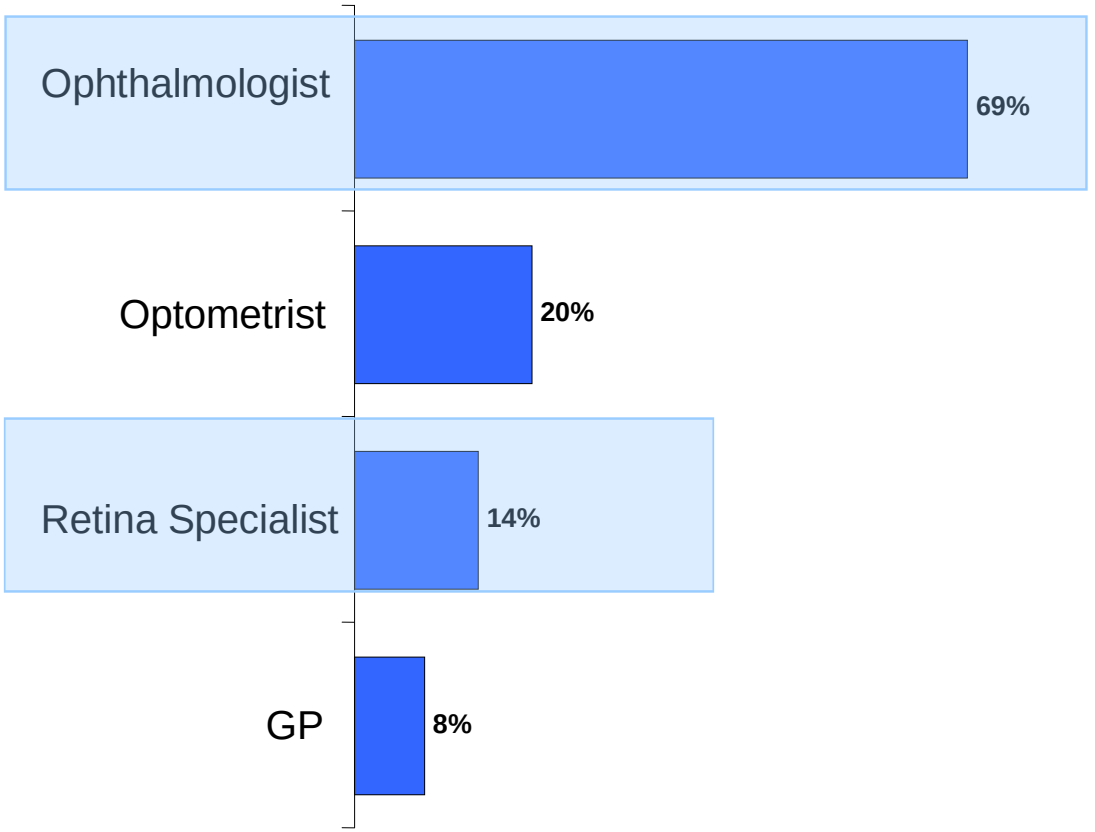
Management and monitoring



Monitoring MD

- Ophthalmologists (83%) are mainly responsible for monitoring MD and in 14% of cases their ophthalmologist was a retina specialist.
- They are also the main diagnosticians for the condition.

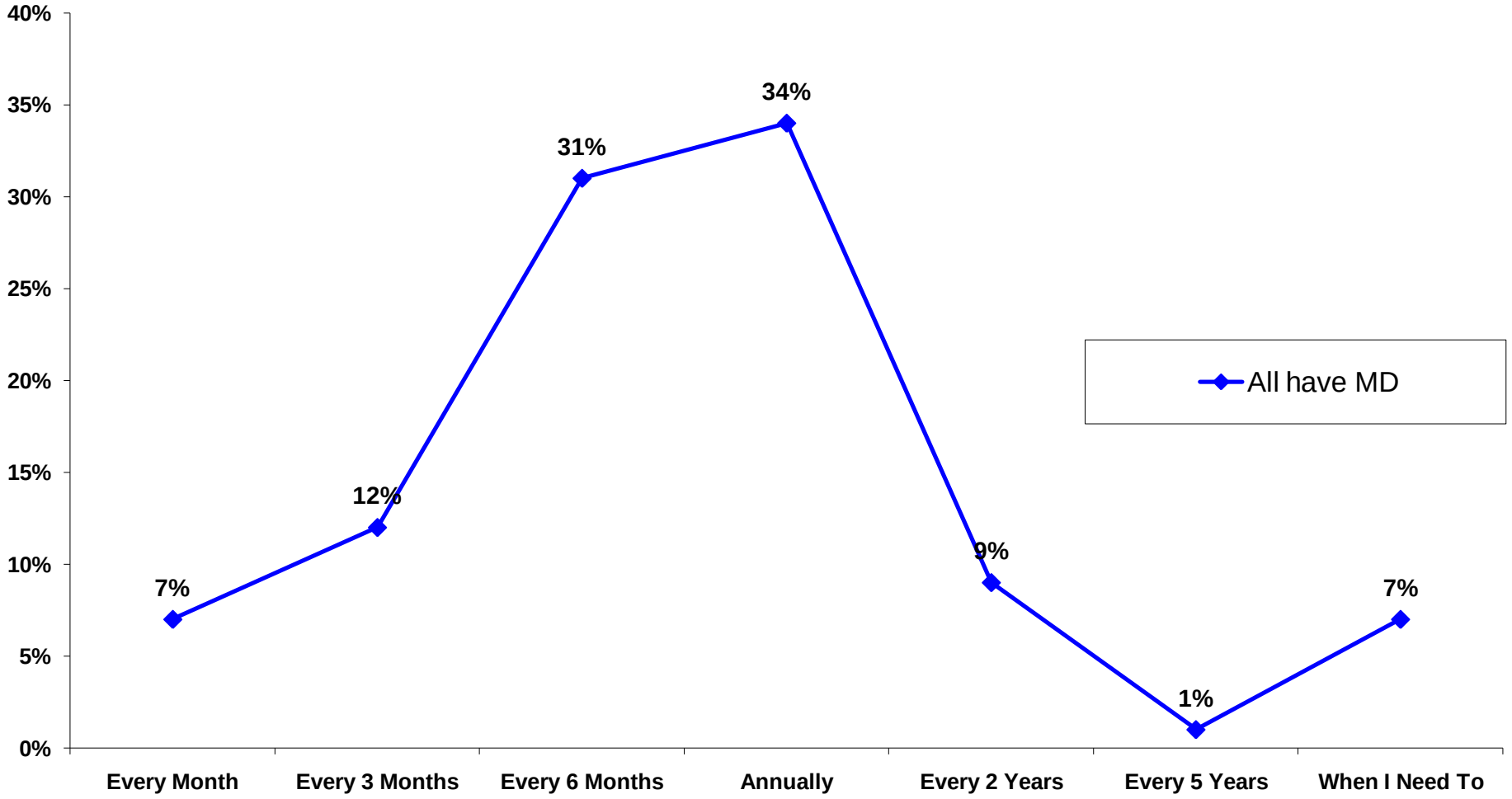


Base n=1560, Have MD (3% didn't answer)

Multiple responses possible

Frequency of visits to monitoring professional-All

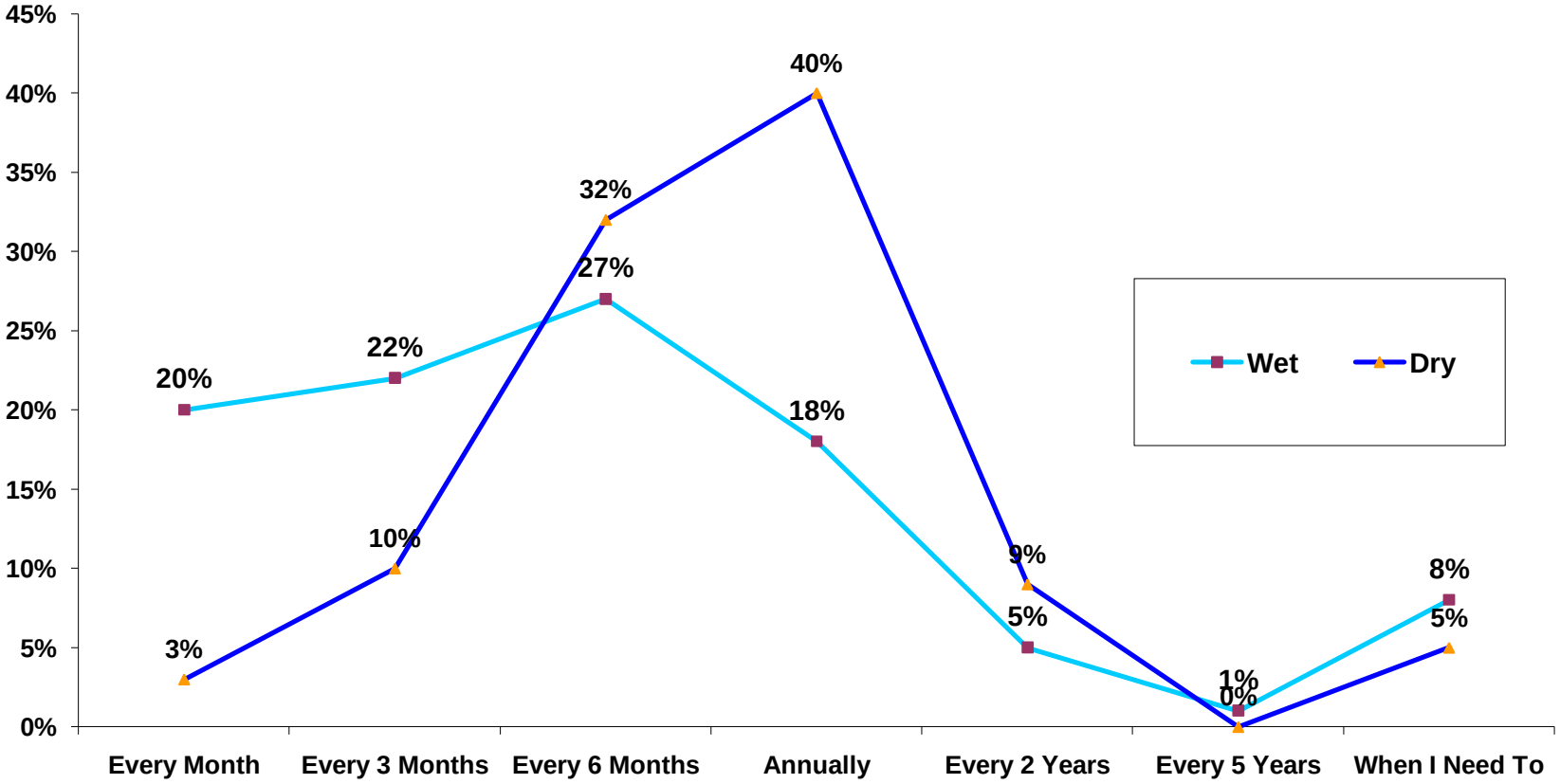
- Half (46%) of the Foundation's members with MD have their condition monitored at least once every six months.
- 80% see their monitoring professional at least once a year.



Base n=1560, Have MD (7% didn't answer)

Frequency of visits to monitoring professional- Wet vs. Dry

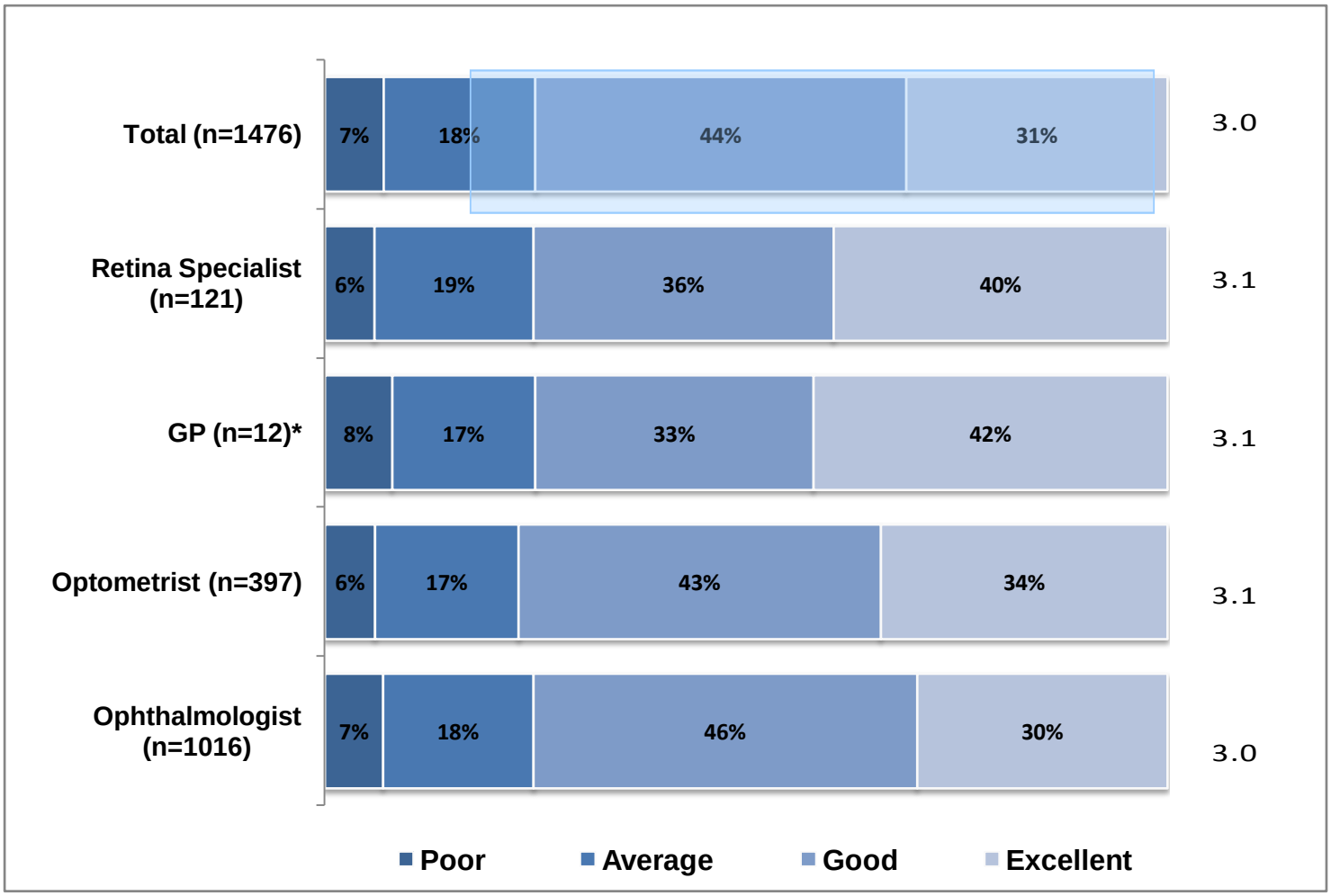
- A larger proportion of those with 'Wet' MD are monitored more frequently, with 69% visiting every 6 months or more, compared to 40% of those with 'Dry' MD.
- It should be noted that currently there is only treatment available for those with 'Wet' MD, so it is to be expected that those with 'Wet' MD are likely to be monitored more frequently. Furthermore, with the recent new treatment available in Australia which involves injecting an anti-VEGF drug into the eye on a monthly basis, it is anticipated that there will be an increase the monitoring frequency of those with 'Wet' MD.



Base n=1560, Have MD (7% didn't answer)

Rating of Communication with Eye Care Professional

- 75% of members who have MD consider they communicate well with their eye care professional.
- 31% consider the standard of communication ‘excellent’.

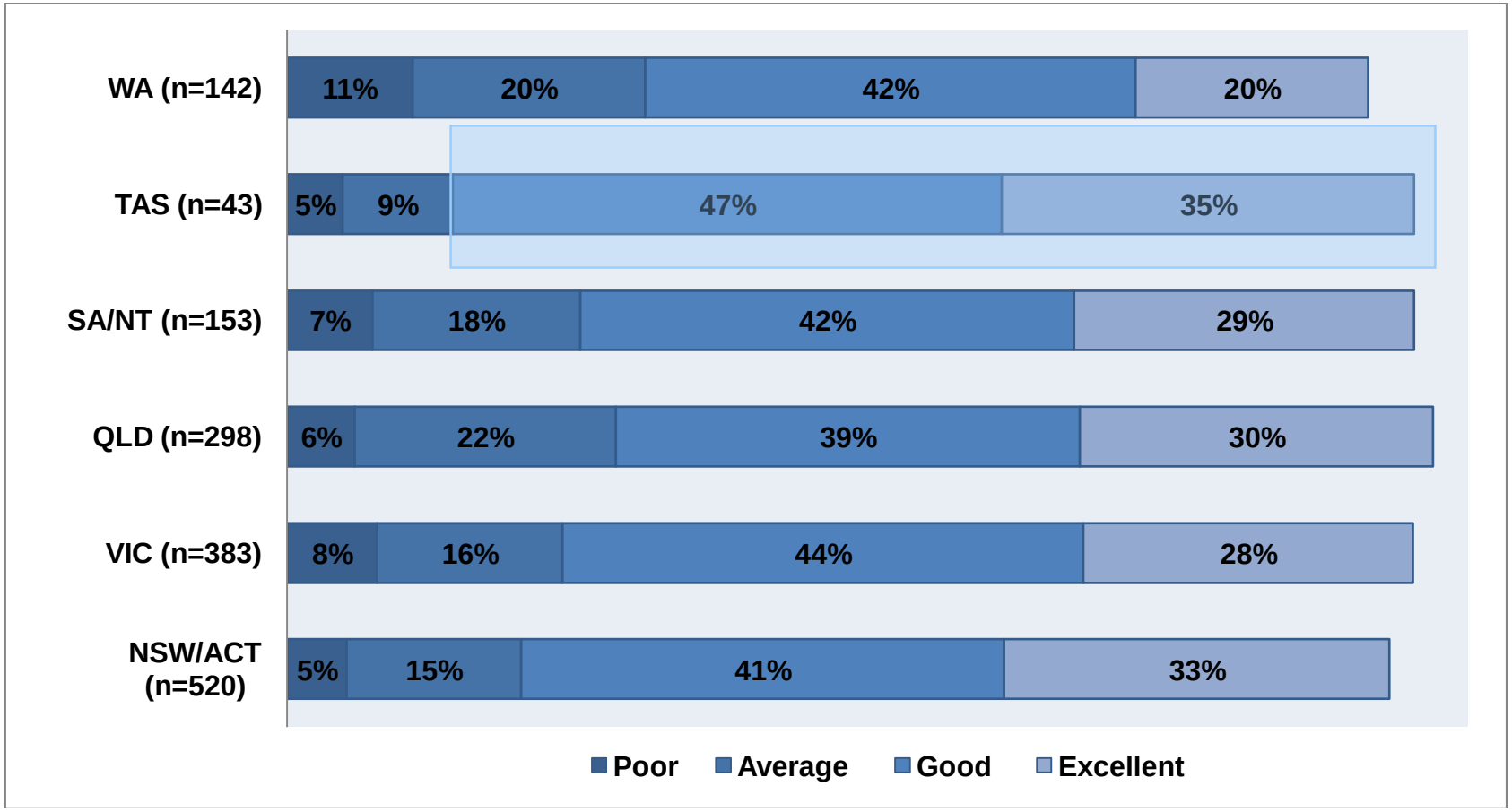


*Caution: small base

multiple responses possible

Rating of Communication with Eye Care Professional by State

- Respondents in Tasmania appear to rate their communication with their eye care professional higher than any other State, with 47% reporting that they felt their communication with their eye care professional was ‘good’ and 35% was ‘excellent’.
- Respondents in Queensland and WA appear to rate their communication with their eye care professional lower than the other State.



Communication with Eye Care Professional

- Respondents were given an opportunity to comment on their communication with their eye care professional.

Type of Comments (n=188)	
Negative	52%
Positive	48%

Some examples of the positive comments made by respondents:

"My optometrist is excellent and very easy to talk to"

A female respondent from Victoria

"The ophthalmologist I have seen now for 9 and a 1/2 years explains what is happening and has taken the fear out of it". A female respondent from Victoria

Some examples of the negative comments made by respondents:

"Not allow enough time for questions such as; what type of MD do I have? And what can be done to treat MD / or slow it down?"

A female respondent from Queensland

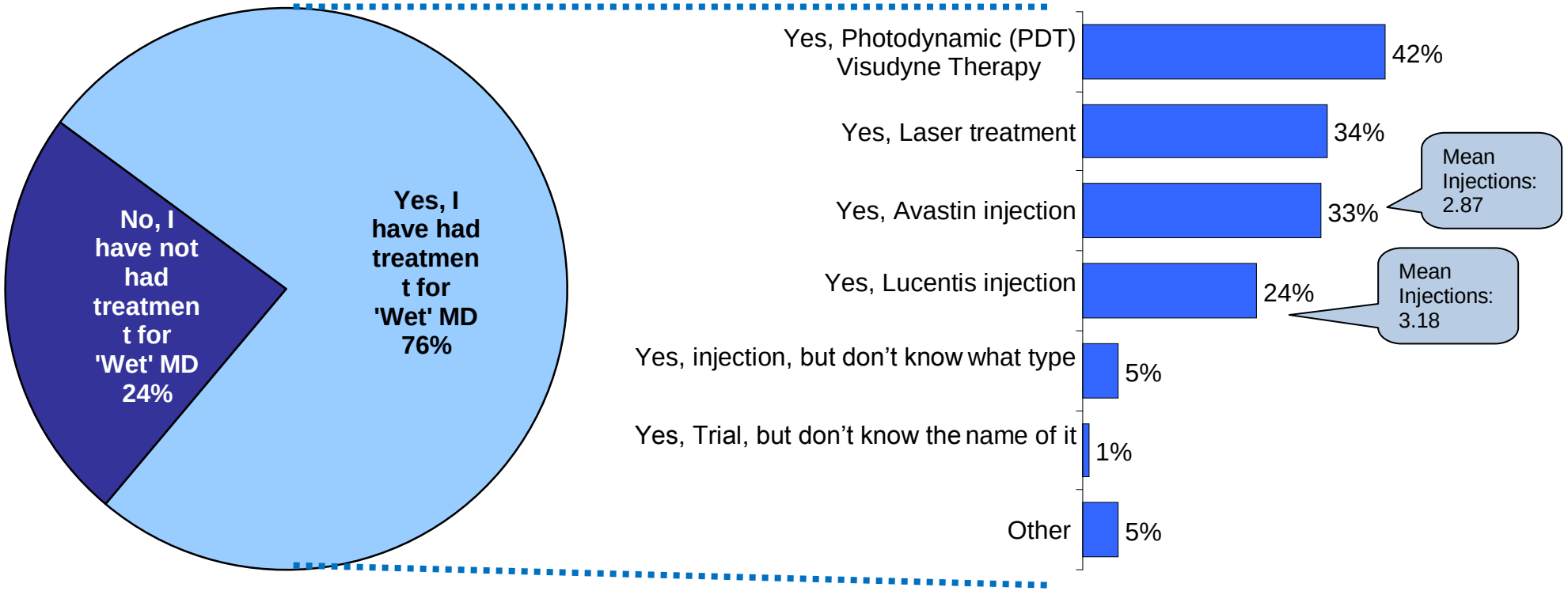
"I would like more information from the Doctor but he always seems to be in a rush"

A female respondent from Victoria

Type of Comments (n=125)	
Limited information	25%
Not enough time - Rushed	18%
Caring	16%
Told nothing can be done	13%
Very informative	10%
Approachable	8%
No opportunity to ask questions	5%
Told to come back when vision deteriorates	3%
Communicates with GP or Optometrist	4%

Treatment types: Wet MD

- 76% of those who have 'Wet' MD have had treatment.
- 42% have had PDT Visudyne therapy.
- Laser treatment (34%) and Avastin injections (33%) are also used by those who have 'Wet' MD respectively.

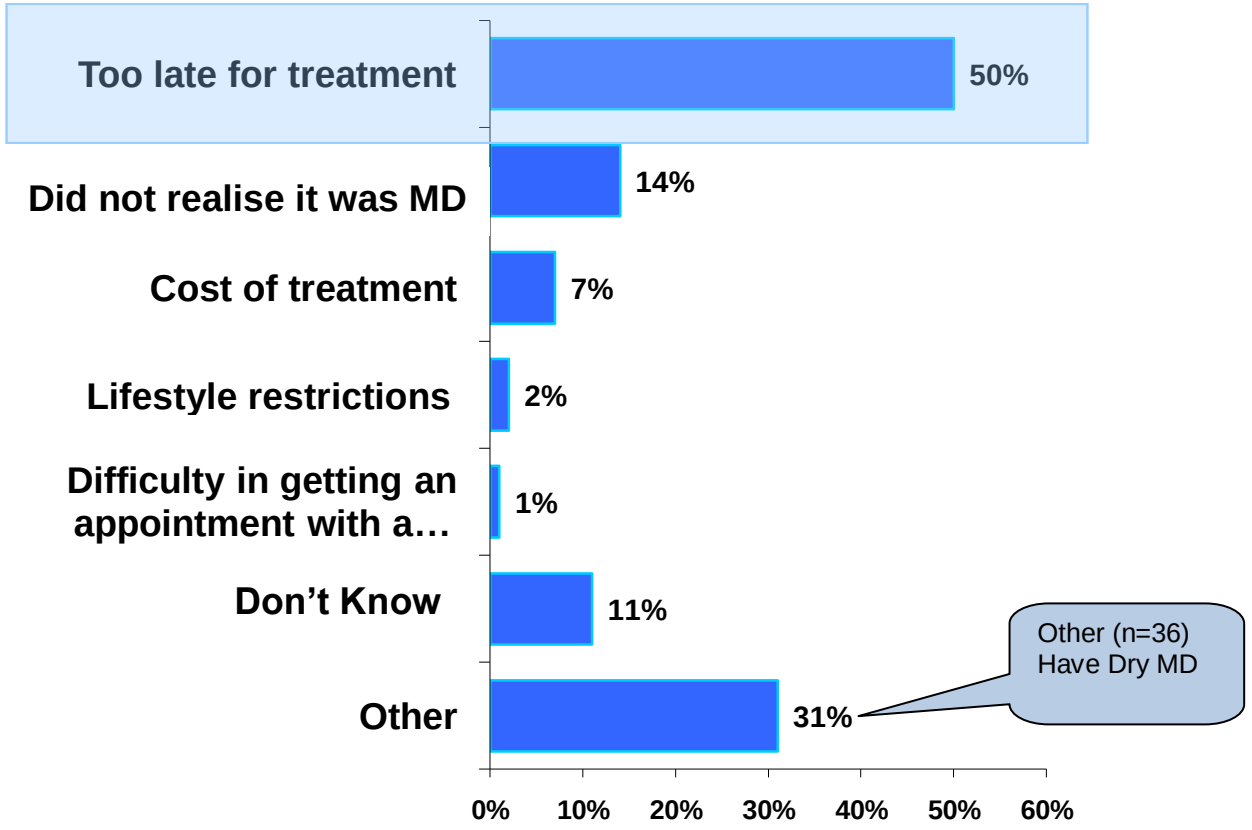


Base n=504, Have wet MD

Multiple responses possible

Reasons for non-treatment of Wet MD

- The major reason for not having treatment for ‘Wet’ MD is that the condition is too advanced. Half (50%) those who have ‘Wet’ MD but have not had treatment give this reason.
- Other reasons such as lack of awareness of MD, the cost of treatment, lifestyle restrictions and difficulty getting an appointment with a health care professional are comparatively minor.

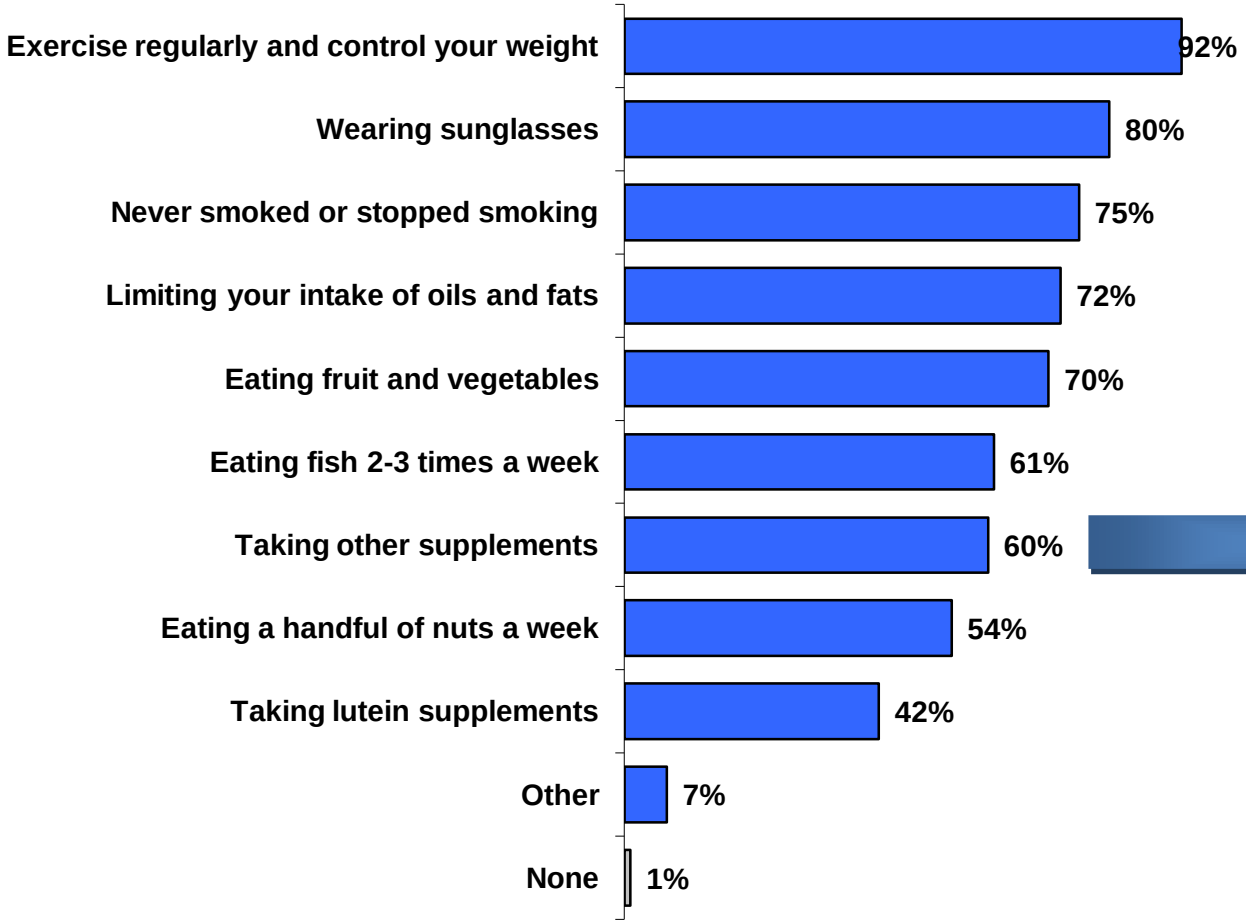


Base n=109, those who have wet MD but have not sought treatment

Multiple responses possible

Steps taken to slow down MD progression

- For those who have MD and are aware of ways to slow the progress of MD, regular exercise, weight control, wearing sunglasses and not smoking are the most common methods used.
- Dietary changes are also popular: limiting oils and fats, eating fruit, vegetables and fish or taking supplements.



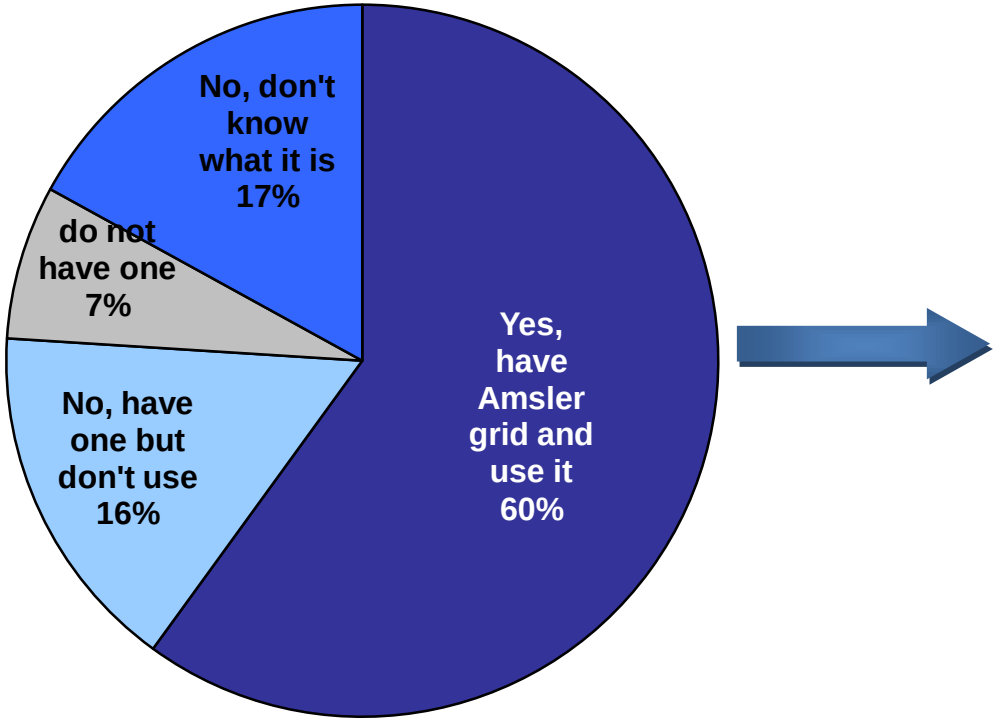
Other Supplements (n=916)	
AREDS Formula	71%
Other Eye Supplements	16%
Other Supplements	6%
Non-Specific or Confused	5%
Multi-Eye Supplements	2%

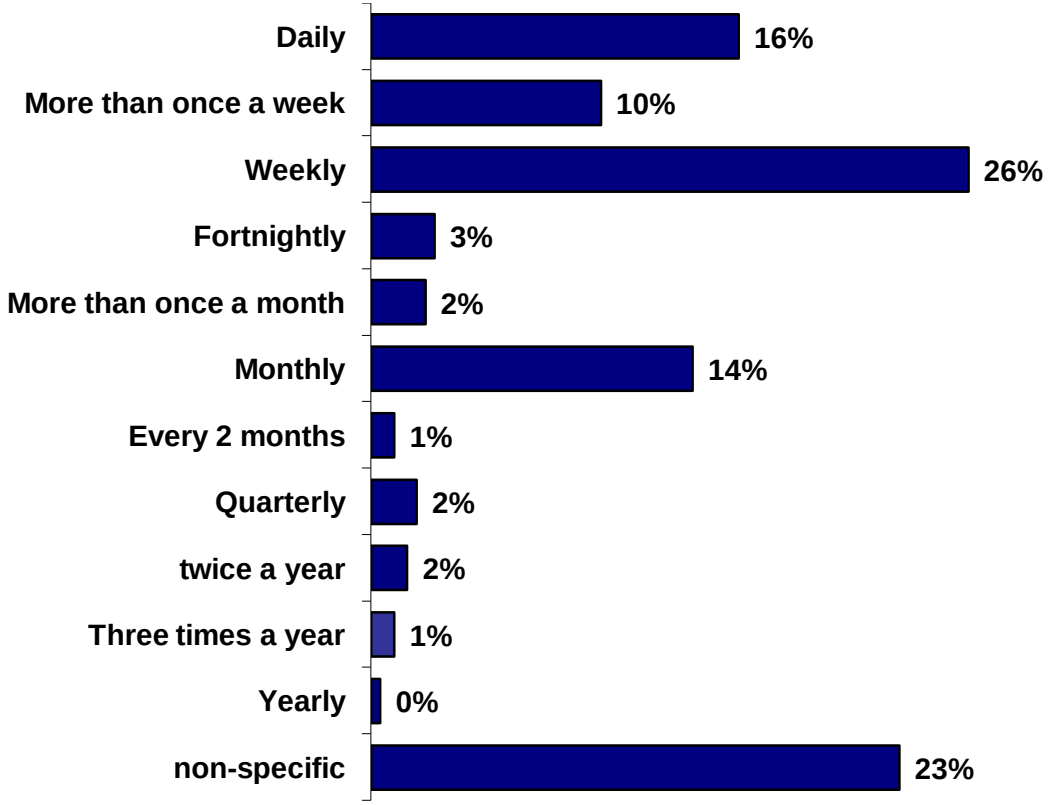
Base n=1075, Have MD and are aware of steps to slow MD progression

Multiple responses possible

Awareness and use of Amsler Grid

- 83% of Foundation members with MD are aware of the Amsler grid.
- However, only 60% of Foundation members who have MD use an Amsler grid.
- Of those using an Amsler grid, 52% use it at least weekly.



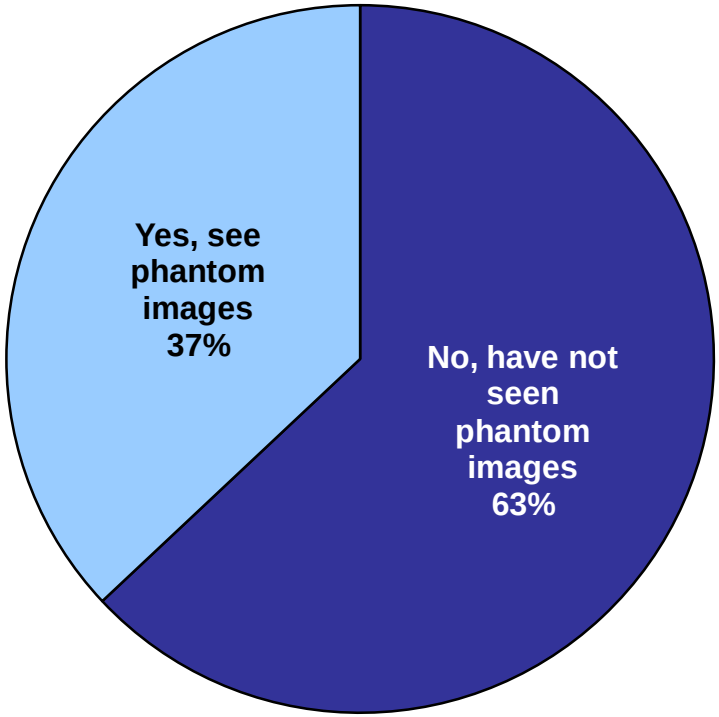


Base n=1560, Have MD (5% didn't answer)

Base n=794, use Amsler grid

Charles Bonnet Syndrome - Phantom Images

- 37% of members with MD have seen phantom images.



Base n=1560, Have MD (6% didn't answer)

Driving ability

- 55% of members with MD who have held a license are still driving.
- Those under 75 and those who have only been diagnosed with the condition within the past three years are more likely to still be able to drive.

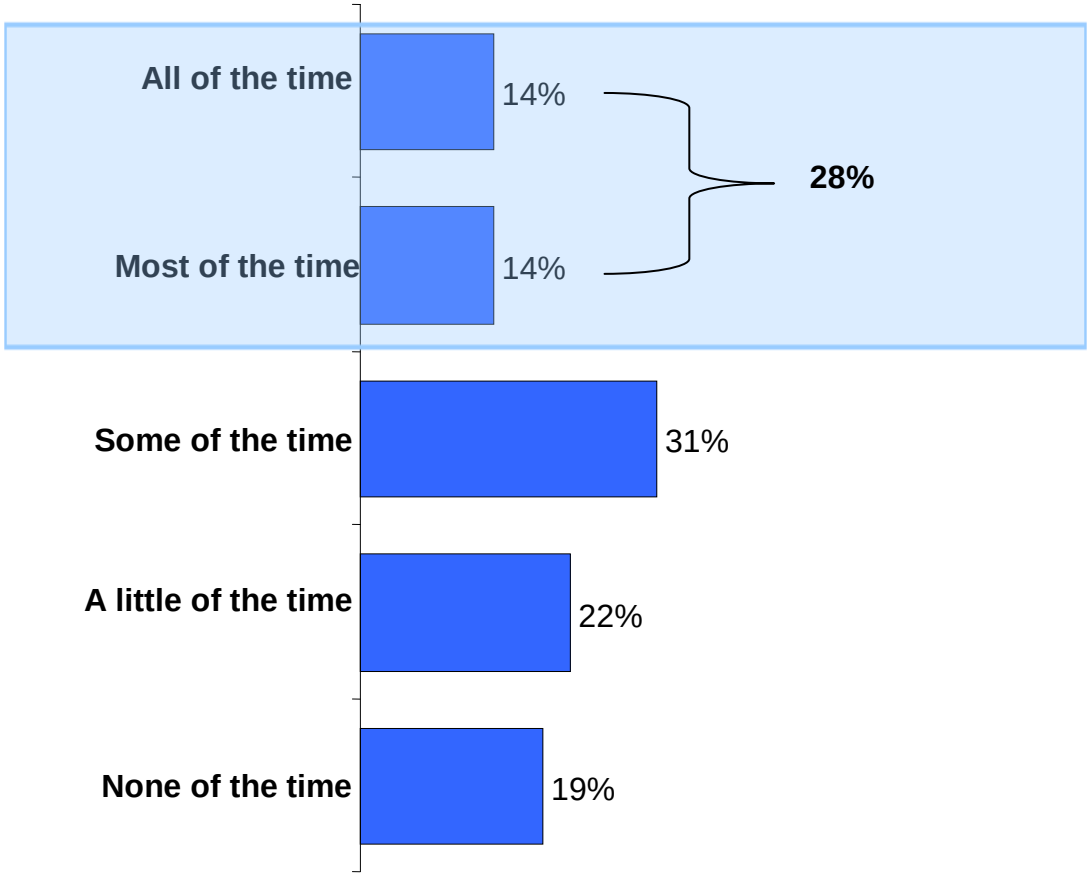
		Age					Length of Time Since Diagnosis			
	Total	**Under 64**	**65-74**	**75-79**	**80-84**	**85+**	**< 1 year**	**1 - 3 years**	**4 - 6 years**	**7+**
Base n=	*1211*	*155*	*310*	*272*	*280*	*192*	*185*	*469*	*274*	*237*
No, I am still driving	**55%**	**80%**	**73%**	**57%**	43%	22%	**74%**	**63%**	46%	34%
I can no longer drive due to MD	33%	5%	18%	34%	43%	66%	14%	25%	42%	57%
My driving ability is limited because of MD	9%	14%	9%	7%	10%	9%	10%	11%	10%	7%
I have a restricted licence (please specify)	2%	1%	1%	2%	4%	4%	3%	2%	3%	3%

Restricted to Driving in Local Area
37%

Restricted to Driving in Daylight Hours
63%

Frequency of frustration with MD

- Overall, 81% of members who have MD experience frustration with their condition.
- 28% with MD reported that they are frustrated by their condition all or most of the time.



Base n=1560, Have MD (3% didn't answer)

Macular Degeneration Foundation™

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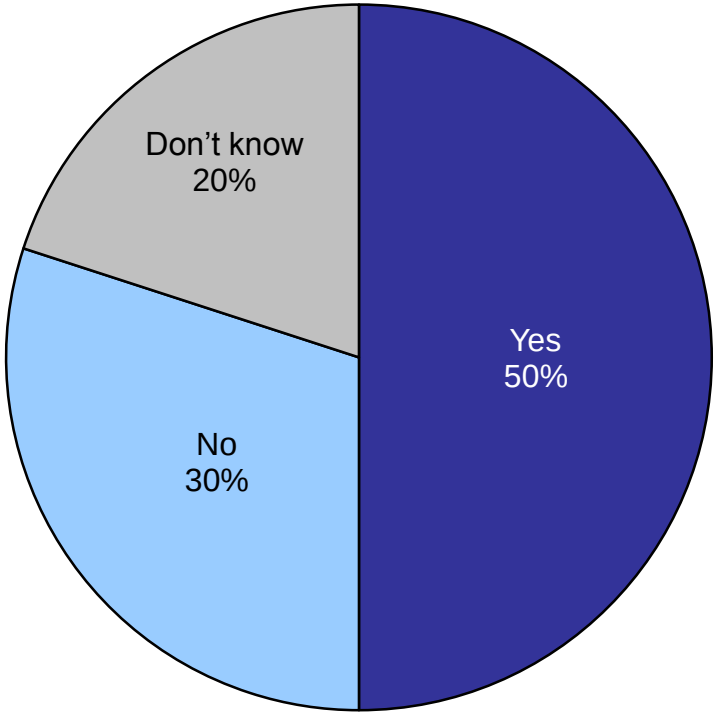
Access and Use of Low Vision Services and Low Vision Aids

Access to low vision services and mobility training

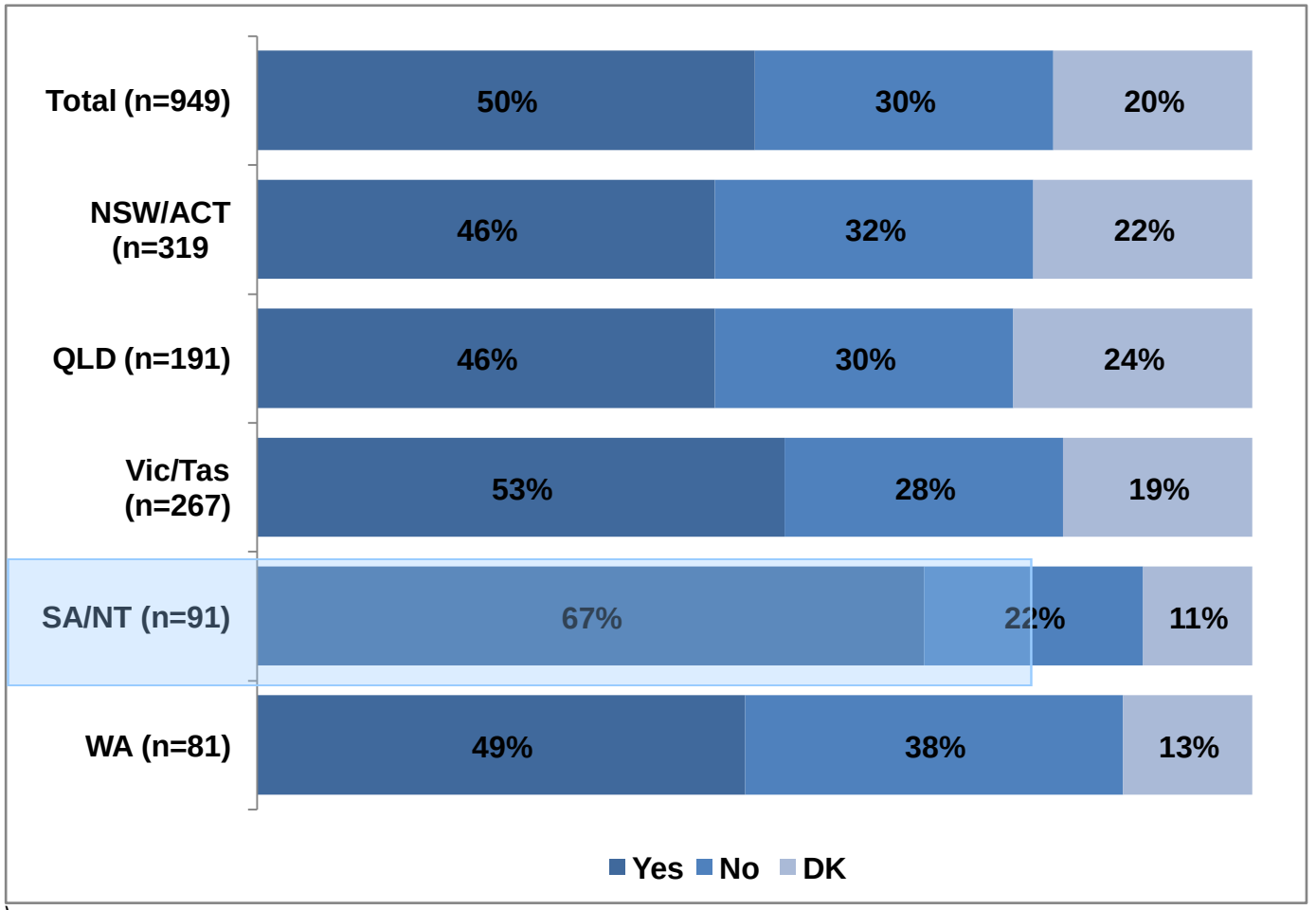
- Of the members who have MD and also they felt they were in need of low vision services, 50% have access to these services.
- 30% do not have access.
- 20% do not know whether they can access these services or not.



Base n=949 All have MD who require vision services

Access to low vision services and mobility training

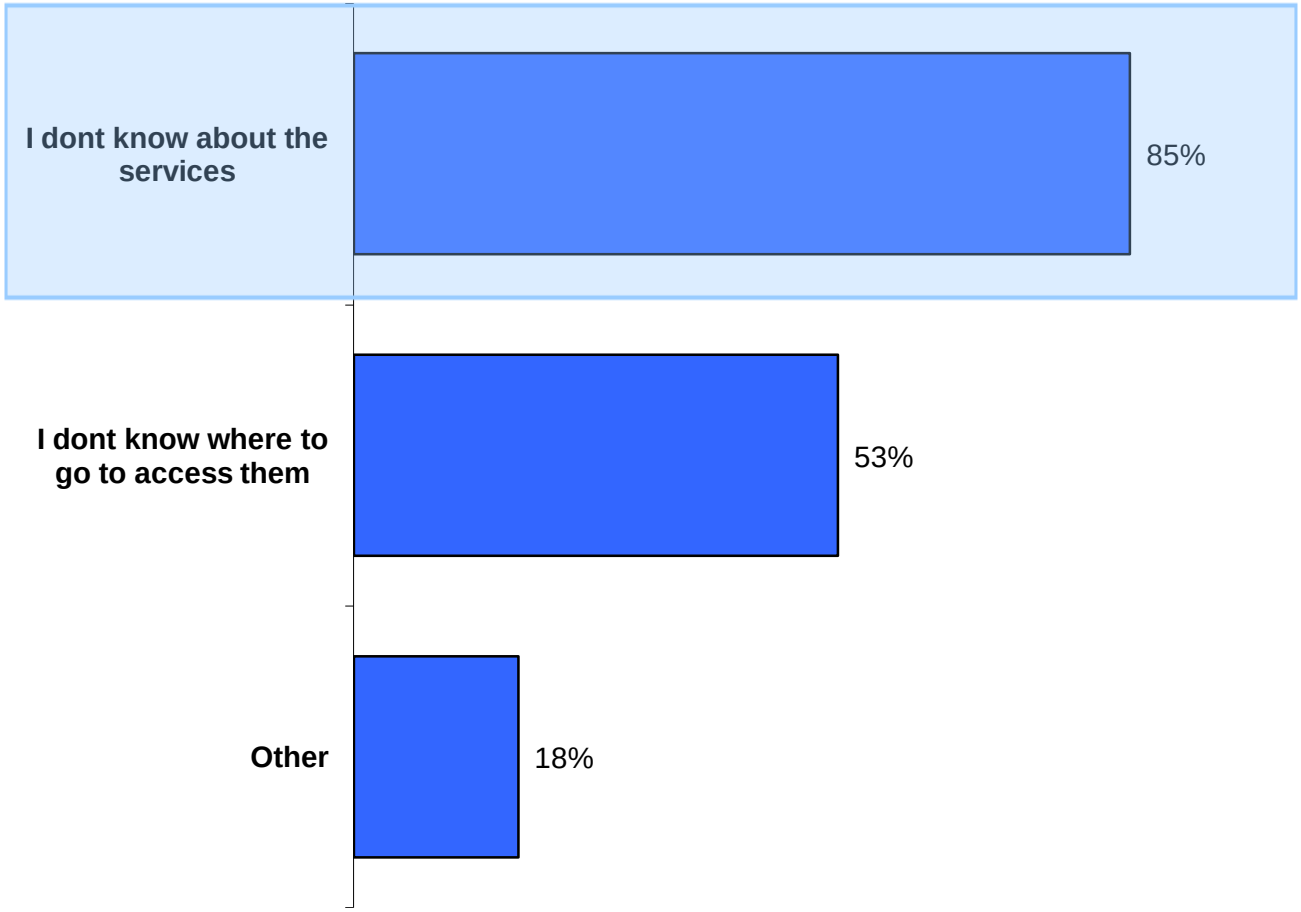
- Nationally, of the members who have MD and also felt they require low vision services, only 50% have access to these services.
- Access is similar in all states, although it is particularly high in SA/NT (67%).



(>1% didn't answer)

Reasons for lack of access to low vision services

- The main factors preventing access to low vision services amongst those who need them are a lack of awareness and not knowing where they can be obtained.

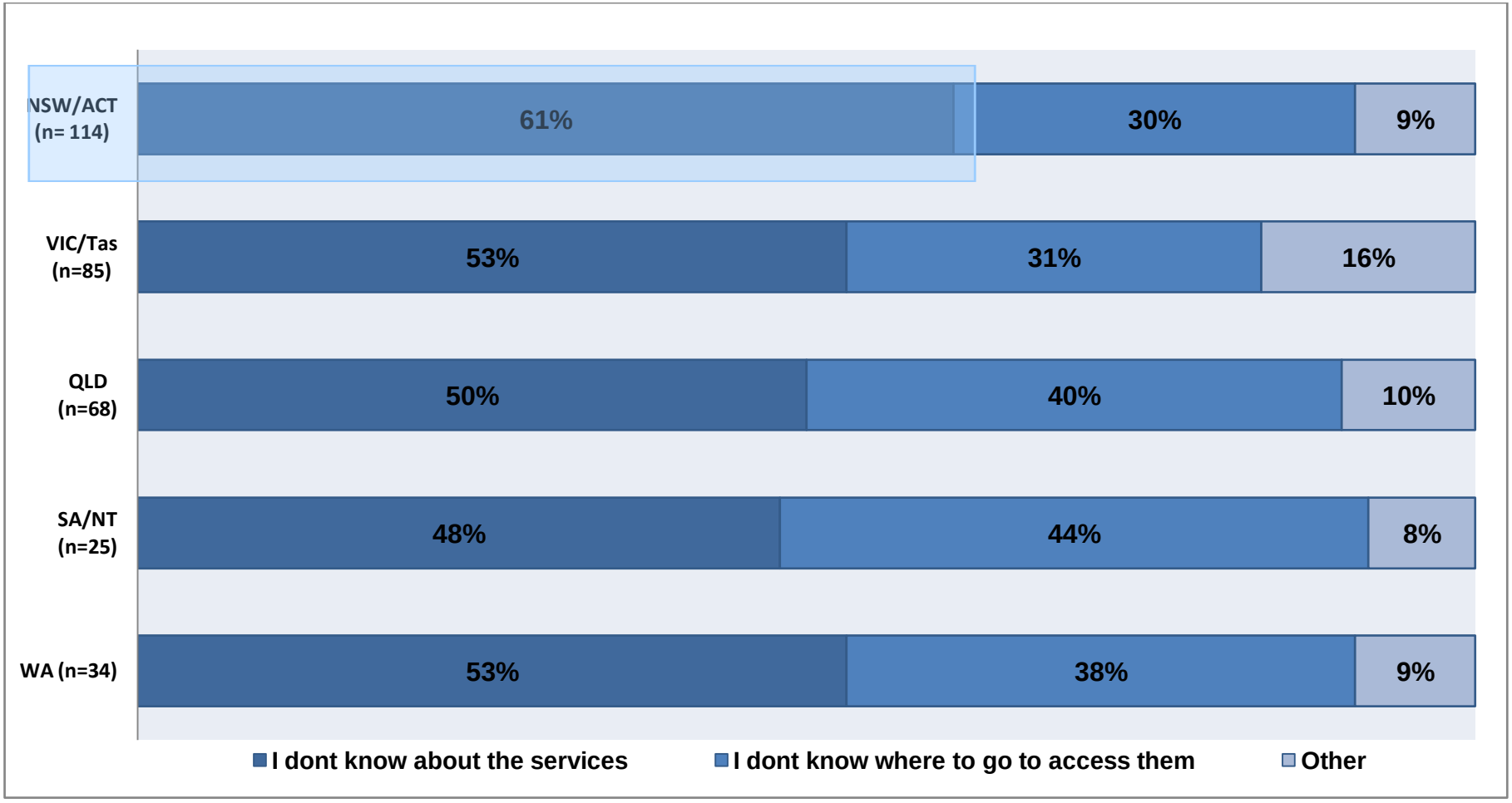


Base n=210, those with MD who do not access Low Vision Services but need them

Multiple responses possible

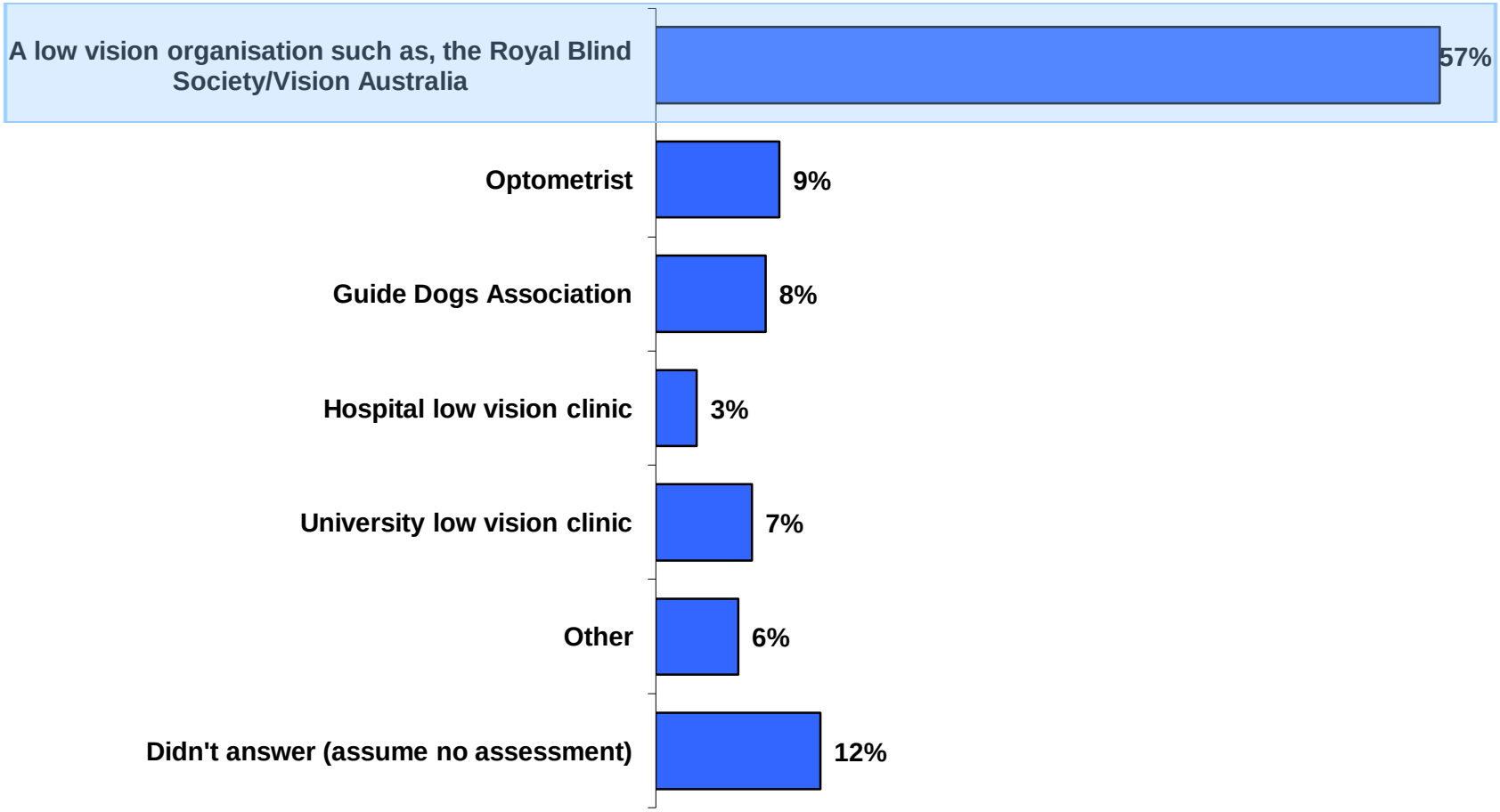
Reasons for lack of access to low vision services by State

- 61% of respondents in NSW and ACT, who felt that they required low vision services, reported that they did not know about low visions services and 30% did not know where to go to obtain low vision services.



Conducting low vision assessments

- Low vision assessments appear to be mainly (57%) conducted by an appropriate organisation (e.g. RBS/Vision Australia).

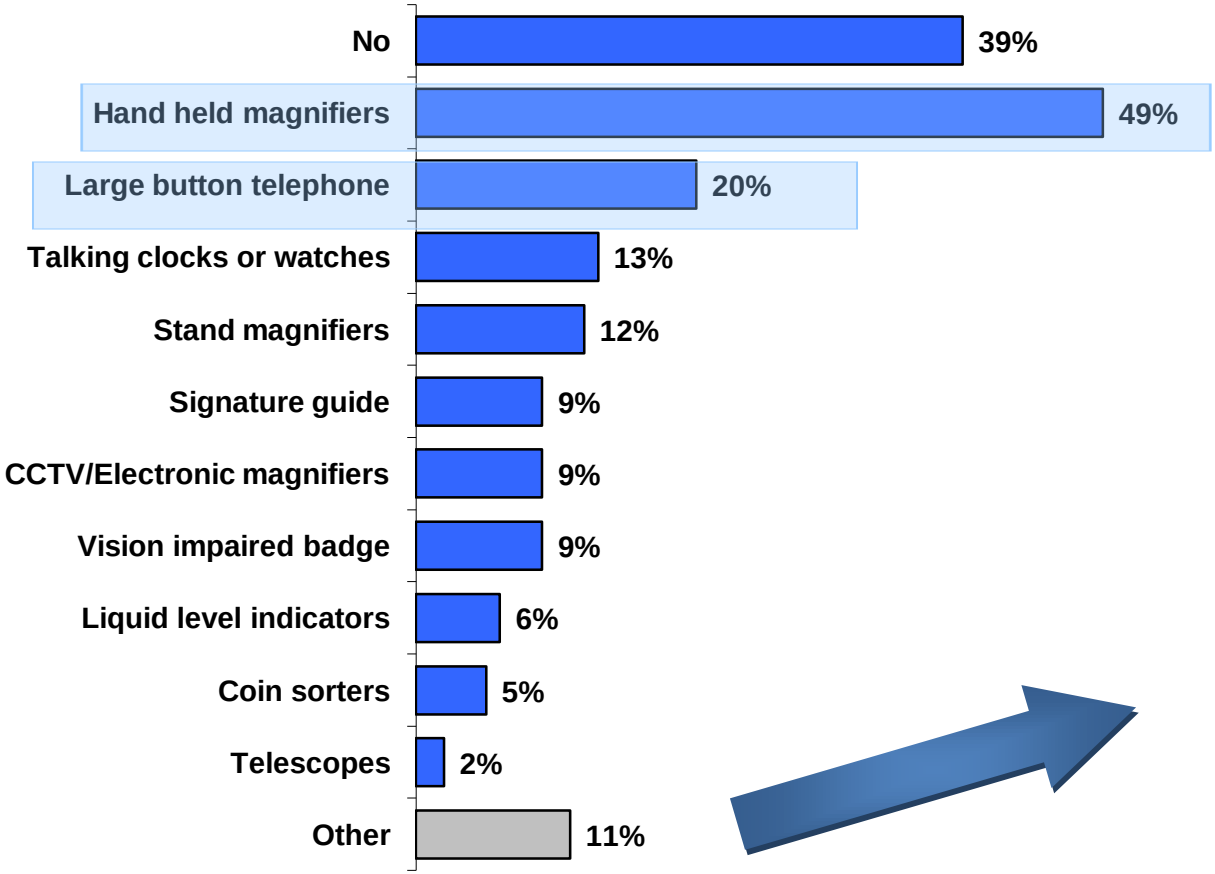


Base n=430, Have MD and have access to Low Vision Services

Multiple responses possible

Low Vision Aid Usage

- 61% of people with MD use a low vision aid of some kind.
- The most commonly-used aid is a hand-held magnifier (49%).
- Large button telephones, talking clocks or watches and stand magnifiers are also employed.



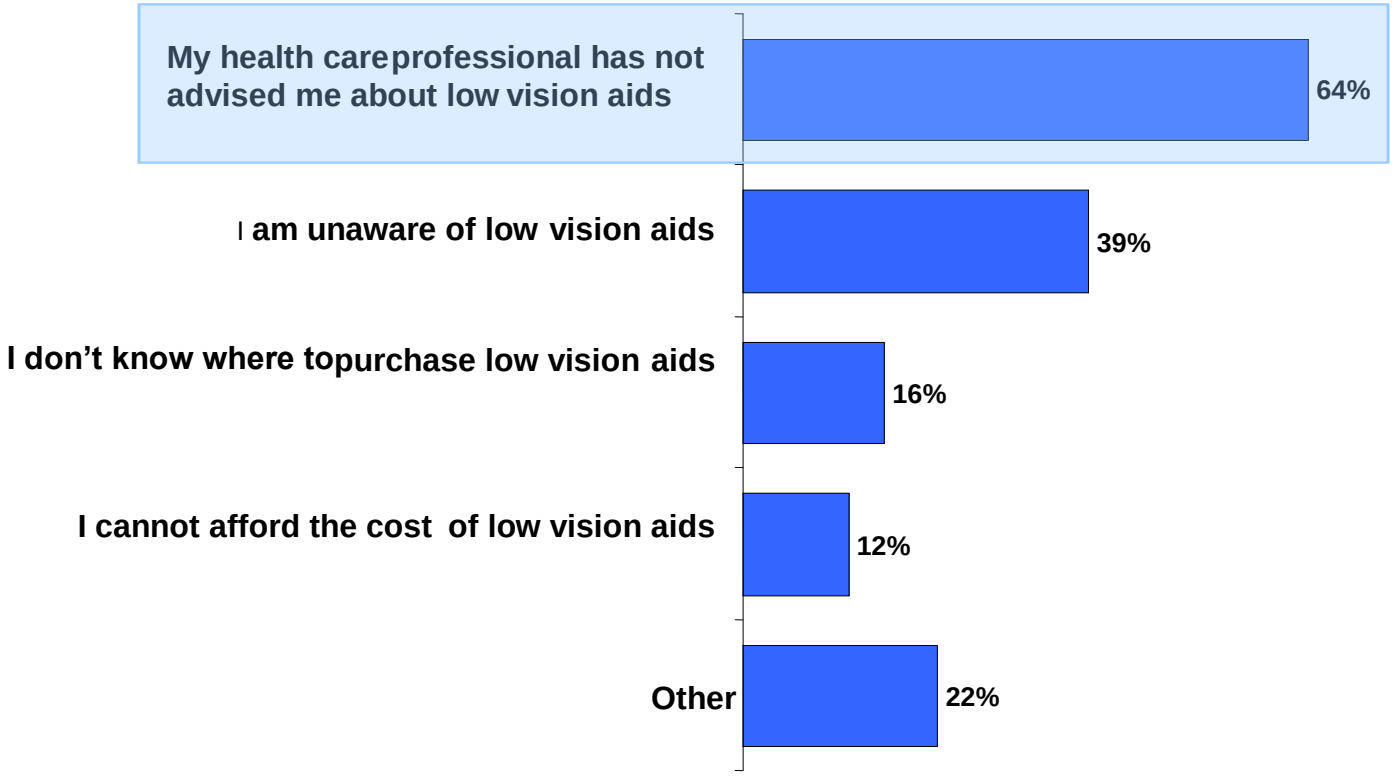
Base n=1560, Have MD (7% didn't answer)

Multiple responses possible

Other (n=145)	
Computer software and hardware	34%
Strong bright lighting	18%
Audio books	12%
White cane	12%
Large print books	10%
TV glasses	6%
CCTV	6%
Magnifier	6%
Binoculars	4%
Large clocks or watches	3%
Markers in kitchen	3%
Talking appliances	2%
Guide dog	1%
Needle threader	1%

Why Low Vision Aids are not used

- Participants with MD, who felt they needing low vision aids, reported that the main reason for not using a low vision aids, was because they had not been advised to by their health care professionals
- A lack of awareness of these aids and where to purchase them are also contributing factors.
- Cost does not appear to be a major issue.

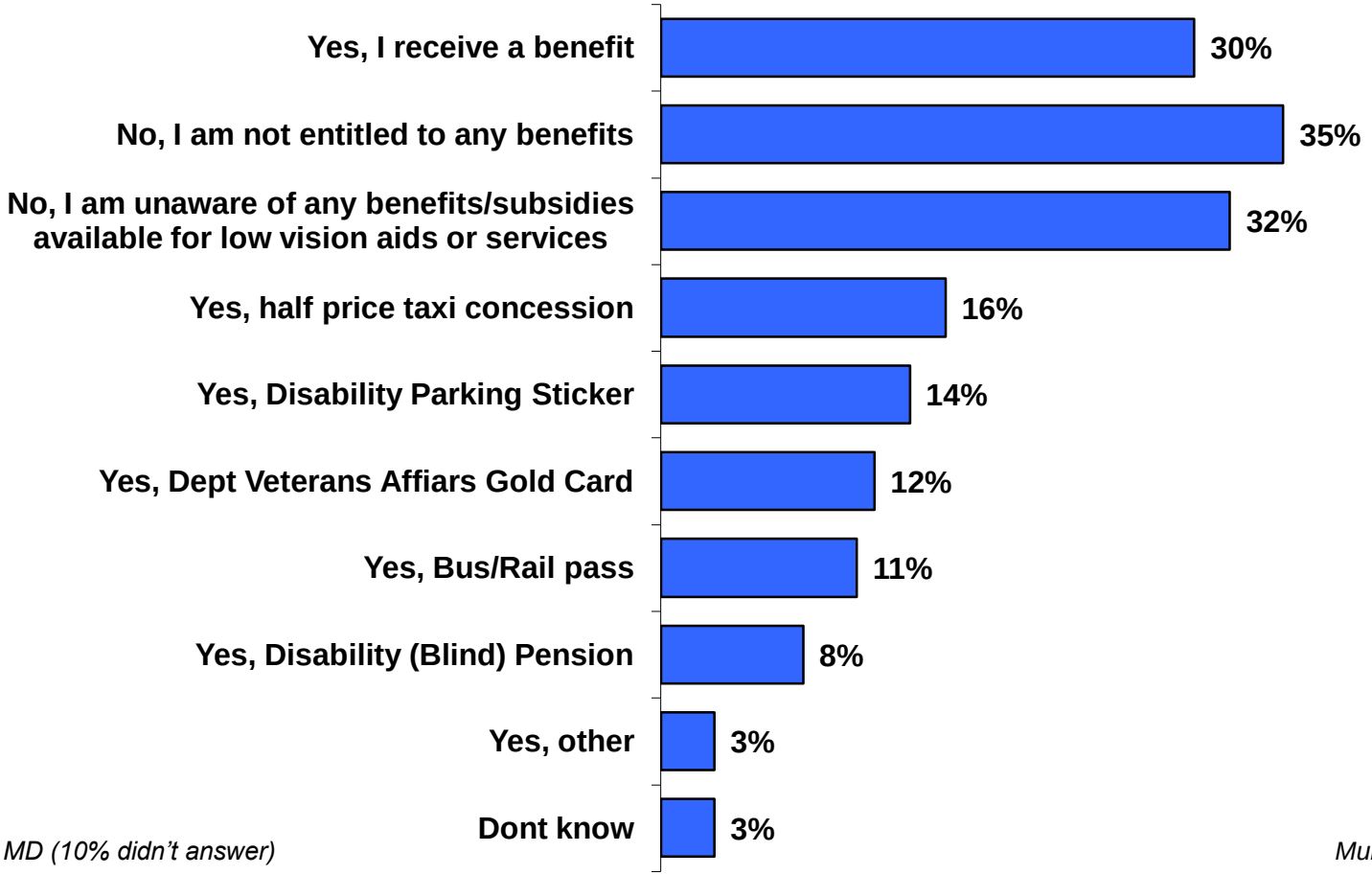


Base n=556, Have MD but do not use Low Vision Aids

Multiple responses possible

Benefits/subsidies received for low vision aids

- Foundation members who have MD fall into three equal groups where benefits or subsidies for low vision aids are concerned:
  - 30% receive a benefit of some kind.
  - 35% is not eligible for benefits.
  - 32% is unaware of the benefits or subsidies which are available.

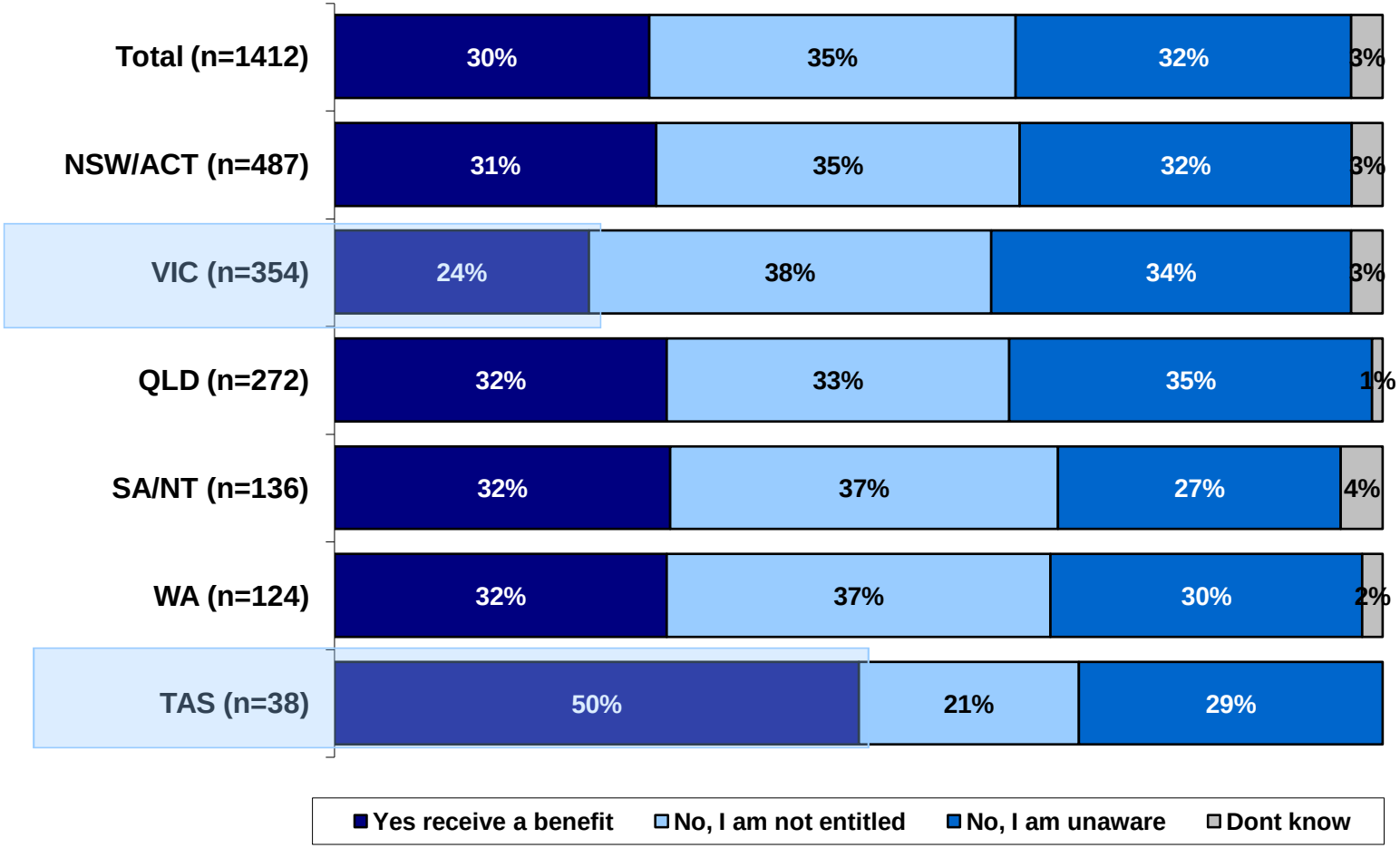


Base n=1560, Have MD (10% didn't answer)

Multiple responses possible

Benefits/subsidies received for low vision aids- by State

- By State, receipt of benefits is equal in NSW/ACT, QLD, SA/NT and WA at around one third.
- Only one quarter receive a benefit in Victoria, contrasted by one half in Tasmania (caution low base).



Base n=1560, Have MD (10% didn't answer)

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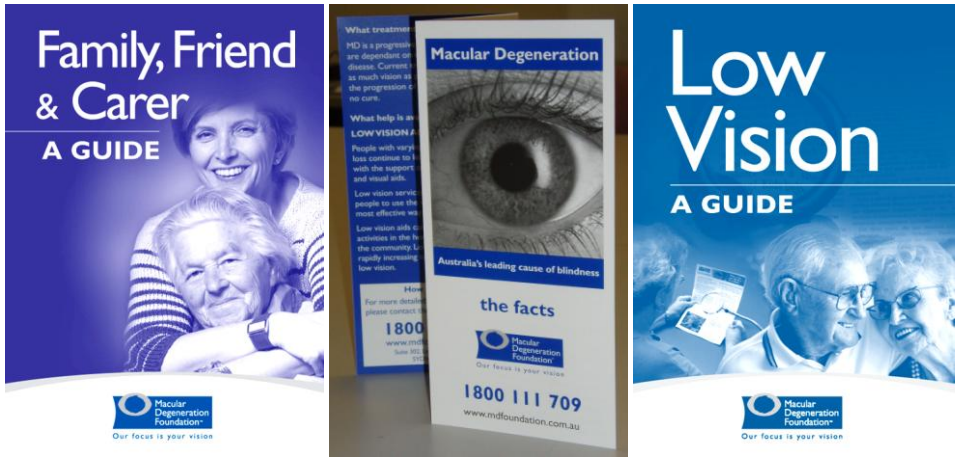
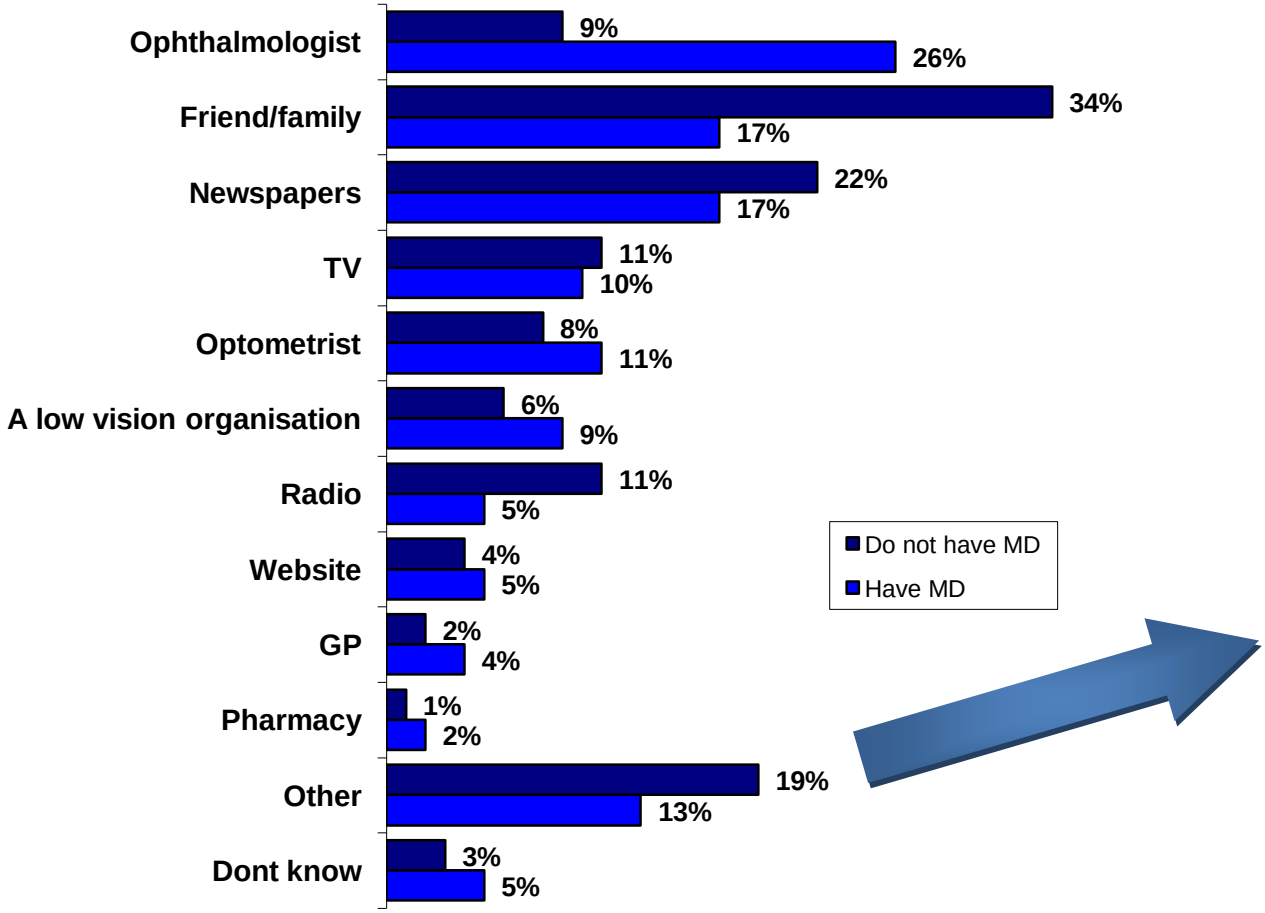
Evaluation of the MD Foundations' Services



Sources of information about the MD Foundation

- Most members became aware of the MD Foundation through their health care professional or family and friends.
- However, those with MD are more likely to have been told about the Foundation by their ophthalmologist while those who do not have MD are more likely to have heard about it from friends/family or the newspaper.



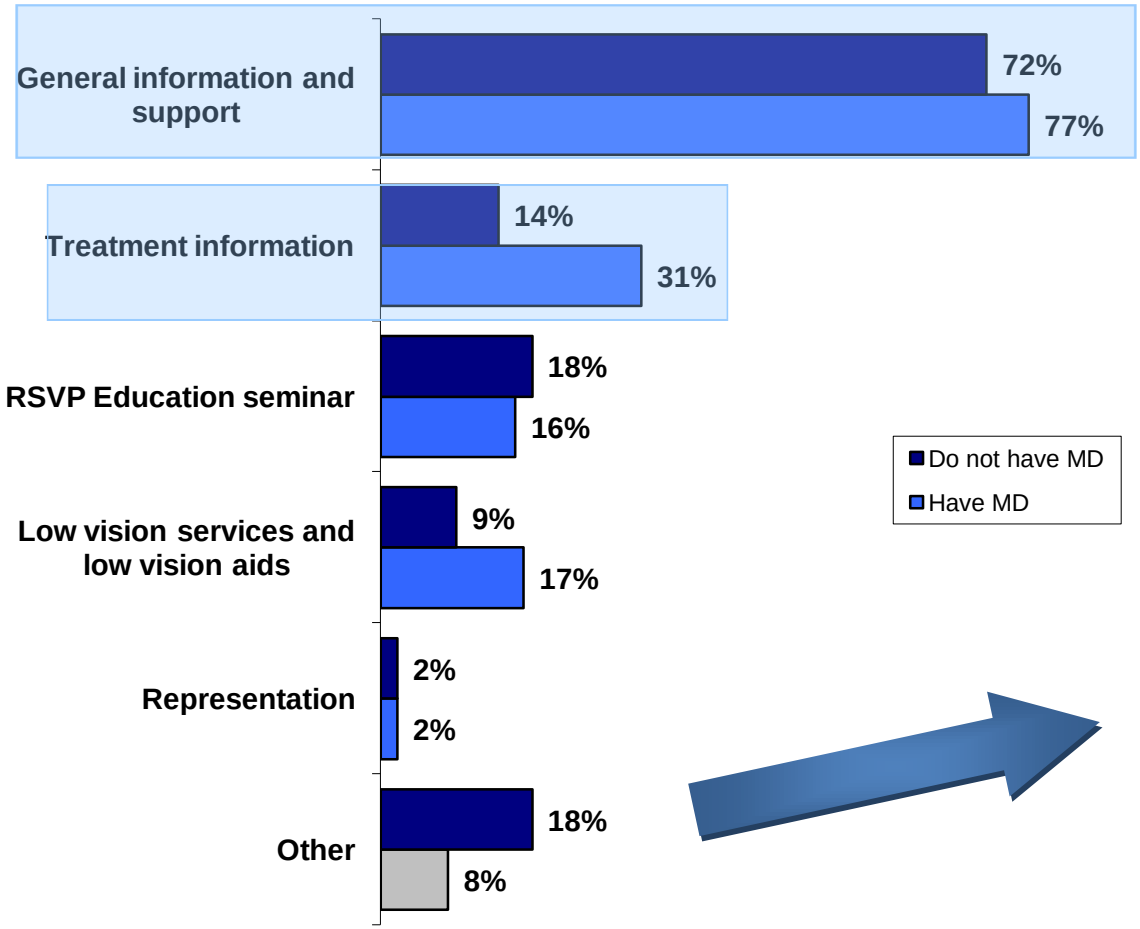
Base n=2010, all respondents (7% didn't answer)

Other (n=200)	
MDF seminar	50%
Eye specialist clinic	10%
Low vision organisation	5%
Print media	8%
Seniors and retirement expo	8%
Vision impaired support group	2%
Internet	2%
Telephone directory	8%
GPs' clinic	1%
Library	2%
Lions club	1%
Friends	1%
Optometrist waiting room	1%

Multiple responses possible

Reasons for contacting the MD Foundation

- The main reason for contacting the MD Foundation is for general information and support (76%).
- This reason is equally important for those who have (77%) and those who do not have (72%) MD.
- 31% of members who have MD request treatment information.



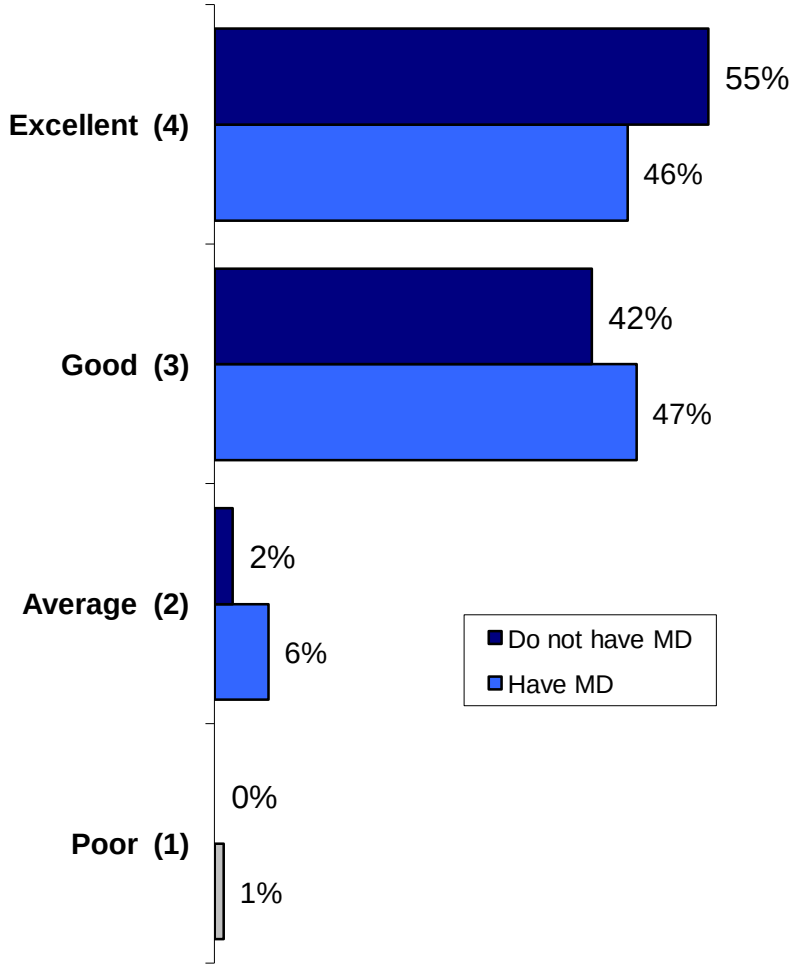
Other (n=54)	
To give donation	35%
Family member made contact on my behalf	22%
MDF seminar	22%
To request an Amsler grid	6%
To participate in research	6%
Don't remember	9%

Base n=2010, all respondents (8% didn't answer)

Multiple responses possible

MD Foundations overall service rating

- Almost all (94%) Foundation members rate the organisation positively overall. 48% regard it as ‘excellent’.
- Those with MD rate the Foundation slightly more positively than those who do not have the complaint.
- There is a very high level of satisfaction with the Foundation’s services amongst all types of members.

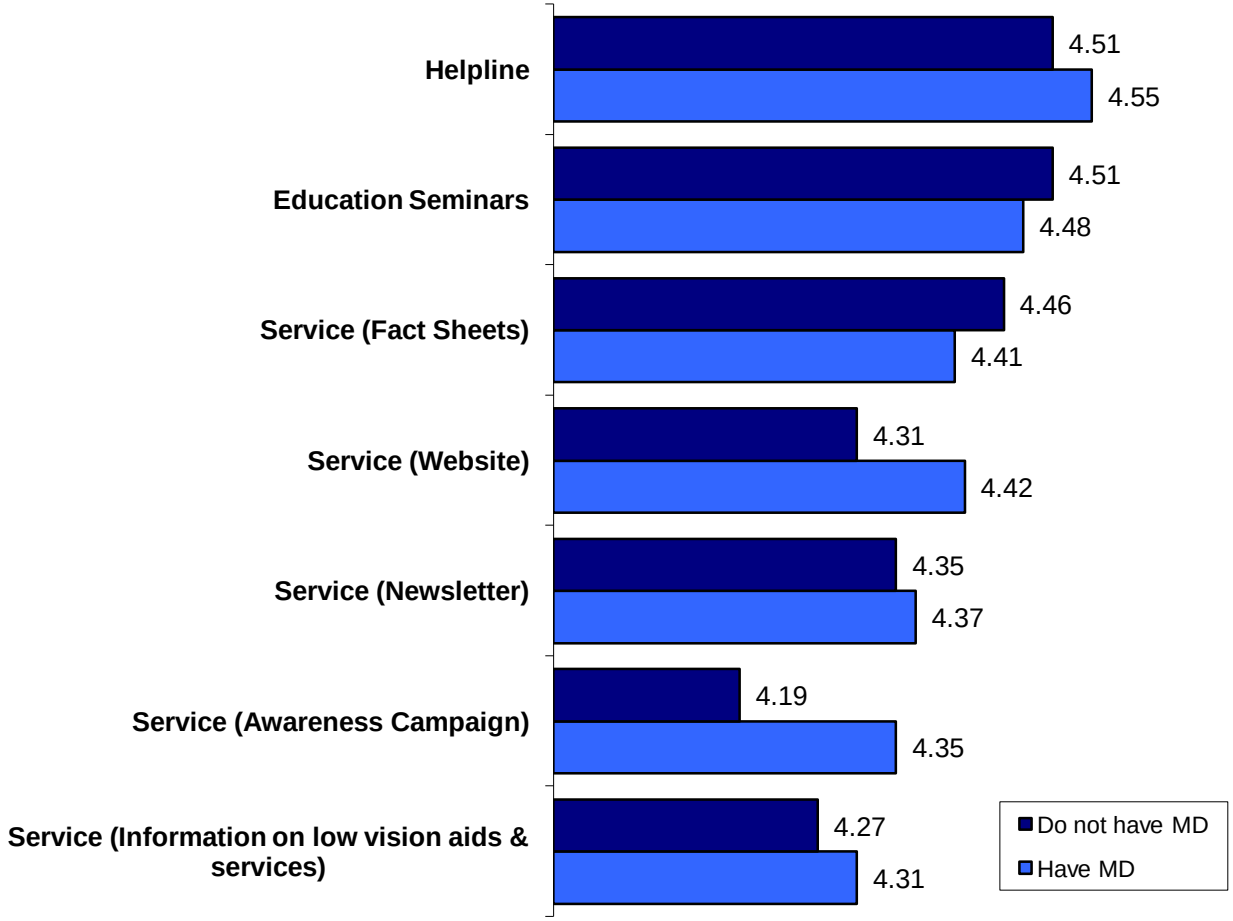


Members Mean Rating: 3.41
Have MD Mean Rating: 3.38
Do not have MD Mean Rating:3.52

Base n=2010, all respondents (17% didn’t answer)

Ratings of the MD Foundations specific services

- MD Foundation members find all its services helpful, regardless of whether or not they have MD.



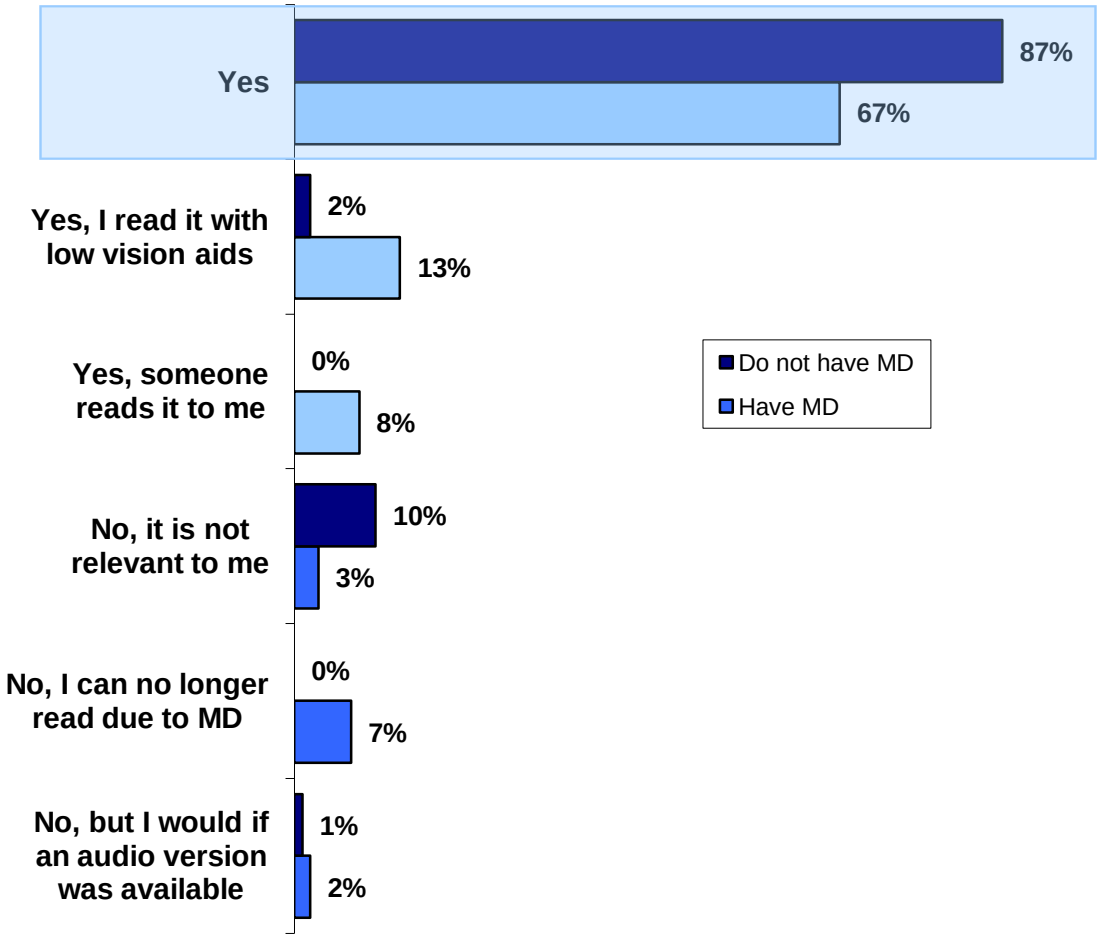
Very Helpful = 5 and Very Unhelpful = 1

Base n=1140, those who have used a MD Foundation Service

Multiple responses possible

Readership of the MD Foundations Newsletter

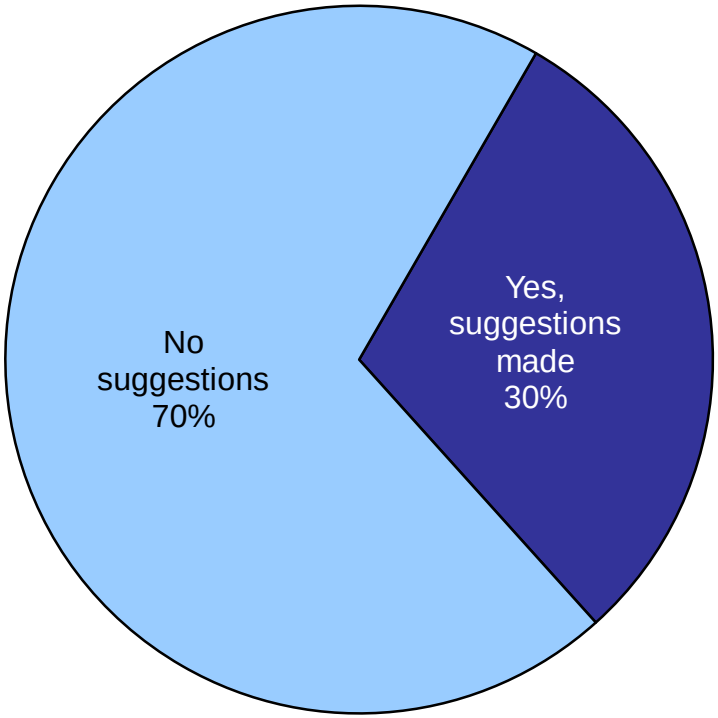
- Readership of the Foundation's newsletter is high, 71% of members read this publication.
- Readership amongst those who do not have MD (87%) is understandably slightly higher than it is amongst those who have MD (67%).



Base n=2010, all respondents (11% didn't answer)

Anything else the Foundation could do for people with MD?

- 30% of members suggest additional services the Foundation could provide.
- The main suggestions they make refer to increased awareness, government assistance and finding a cure for MD.



Other (n=129)	
MDF help - raise awareness	19%
MDF help - government cost of treatment	17%
MDF help - find a cure or means of prevention	16%
MDF help - lobby government LVA and services	12%
MDF help - Support	12%
MDF help - Education	11%
MDF help - improved services in rural areas	5%
MDF help - Government research funding	3%
MDF help - government support	3%
MDF help - advice on slowing down progression	2%

Base n=2010, all respondents (44% didn't answer)

Multiple responses possible

Anything else the Foundation could do for people with MD?

- Respondents were given an opportunity to comment on what they felt the Foundation could do to help those with MD.

Examples of comments participants made regarding how the MD Foundation may help those with MD:

In regards to suggestions about increasing awareness:

"*Advertise to folk who don't have regular eye checks, perhaps leaflets to GPs/ hospitals retirement villages, shire council's community services".*

A female respondent from NSW

In regards to suggestions about seeking more government assistance:

"It is about time the government took notice of the disease and put some money in to research".

A female respondent from NSW

In regards to suggestions about advocacy to the government for assistance with low vision aids:

"Low vision aids are far too expensive. People with MD are mostly pensioners. Organise government grants for people for need to use these aids make sure aids available though libraries".

A female respondent from Queensland

Conclusion

The ultimate objective of this study was to ascertain the experiences, the needs and the extent of knowledge about the disease amongst the MD community in Australia. In gaining a clearer understanding of the experiences of the MD community in Australia, the Foundation aims to use the findings of this study to identify areas where the Foundation can better assist those affected by MD, their families and carers. The following is a summary of the key findings.

Awareness and Diagnosis of MD

- Foundation members mainly learn about MD through personal contact, those with MD learn from a health care professional and those who don't have MD learn from family and friends.
- 83% of members who are with MD have a vision check at least once a year, usually by an ophthalmologist.
- 78% of the Foundation's members have MD, the dominant form being 'Dry' (58%).
- On average, those who have MD were diagnosed with the condition, usually by a specialist, in the past four years, with an average period of 13.88 weeks between the appearance of symptoms and the diagnosis.
- 22% of members who have MD reported having a family history of the disease.
- 27% did not know whether there was a family history of the disease.
- Almost all of those who have MD (97%) informed their families that they have developed the condition. They encouraged their families to take precautions against MD, such as having regular eye checks, dietary changes, stopping smoking and wearing sunglasses.

Management and monitoring

- Half of those who have MD (46%) visit their eye care professional, usually a specialist, at least once every six months.
- The majority (75%) feel they communicate well with their doctor.
- The majority (76%) of those who have 'Wet' MD have had treatment, usually with PDT Visudyne Therapy, laser treatment or Avastin injections (the majority of respondents completed the questionnaire before Lucentis was placed on the PBS).
- Those who have not had treatment for 'Wet' MD mainly reported that it was too late to do so.

- 25% of members with MD are not aware of steps they can take to help slow down the progress of the disease.
- Information regarding the steps that might help slow down the progression of the disease is usually provided by specialists or the MD Foundation.
- Regular exercise, weight control, wearing sunglasses, not smoking, dietary changes and taking supplements are the main steps taken by those with MD to help slow the progress of the disease.
- 83% of the Foundation's members with MD are aware of the Amsler grid, while 60% use this management tool.
- 37% of members who have MD have experienced phantom images.
- 55% of those who have MD and have held a licence are still driving; the majority are those under the age of 75 who have had the condition for less than three years.
- 81% of members with MD experience frustration with their condition, 28% continually.

Access to and use of low vision services and aids

- Only 50% of the members who have MD and require low vision service have access to these services. This low level of penetration is mainly due to a lack of awareness of such services.
- Low vision assessments are usually carried out by a low vision organisation such as the Royal Blind Society and Vision Australia.
- 61% of the members with MD need a visual aid of some kind; the most common used is a hand-held magnifier.
- In relation to subsidies for low vision aids for those with MD, the results fall into three equal groups. One third receives a benefit of some kind, one third is ineligible and the remaining third is unaware of the subsidies which are available. However only one quarter receive a benefit in Victoria.

Evaluation of the Macular Degeneration Foundations' services

- Most members became aware of the MD Foundation through their health care professional (35%) or family and friends (21%).

- Members mainly approach the Foundation for general information and support (76%), although those who have MD also requested information on treatment.
- There is a very high level of satisfaction with the Foundation's services amongst all types of members.
- Readership of the Foundation's newsletter is high, 71% of members read the publication.
- Members suggested that the Foundation could further help those with MD, by increasing awareness of MD, seeking more government assistance for a variety of needs and finding a cure or means of preventing MD.

It is clear from the results that there are a number of areas that need addressing, such as the lack of knowledge about the various low vision services available, amongst those with MD. Also the high percentage of those suffering from some sort of frustration due to their vision impairment is another aspect that requires further investigation. The high percentage of those with MD reporting to have experienced phantom images is an aspect of the disease that requires further focus on education and awareness not only amongst the MD community but also amongst health care professionals. There is also room for increased education regarding the importance of using an amsler grid on a regular basis.

The study also demonstrates that the vast majority of those who use the Foundations' services are highly satisfied with services that the Foundation provides.

One of the limitations of this study is that the participants may not be a representative sample of people with Macular Degeneration in the general Australian population, as the sample was drawn from the MD Foundation's database. Those on the Foundation's database receive regular information about Macular Degeneration, and so are likely to be well informed people, who are more aware of risk factors and risk reduction steps. Others who have never made contact with the Foundation may be less knowledgeable about Macular Degeneration

The results of this study will guide the Foundation's future education program and awareness campaigns. The results of this study will also be used to guide the Foundations' next social research study; *'Project Vision 3'.*

Acknowledgement

The MD Foundation's research project is an ongoing initiative to better serve the MD community in Australia. The project is funded by the MD Foundation, with support from Blackmores Ltd and the generous donations from the MD community. The project is also a direct result of Dr. Paul Beaumont's commitment to the MD community. The Foundation is also grateful for the support and assistance of the Medical Committee, the Client Services Committee and Professor Paul Mitchell, whose contribution in the design and development of this project was invaluable.

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