

## PERSPECTIVE

# Empowering patients with high myopia: The significance of education

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## Abstract

**Purpose:** To investigate the status of patient education among highly myopic individuals focusing on the presence, sources, content, timing of the education and impact on patients.

**Methods:** Self-reported data were collected through an online 13-item questionnaire consisting of open and multiple-choice questions. The questionnaire was sent to 250 highly myopic members of a patient organization in the Netherlands, of whom 128 (51%) responded.

**Results:** At least one acute event had occurred in 66% (84/128) of participants at the time of the questionnaire. Among all participants, 25% (32/128) had not received patient education regarding alarm symptoms for any of these events. Among those who had been informed, the ophthalmologist was the most frequent (57%, 73/128) source of information. Participants who visited the ophthalmologist annually were more frequently informed than participants without annual visits (53%, 26/49 versus 26%, 9/35,  $p=0.002$ ). Those not informed were more likely to have a more than 3 days patient delay (92%, 12/13). Doctors delay was also present; 26% (22/84) of the participants with alarm symptoms had to wait 2 or more days before the first appointment. Long-term consequences of myopia had been discussed with 102 participants (80%, 102/128), again with the ophthalmologist as the most frequent source (59%, 76/128).

**Perspectives:** Many myopic individuals have not been educated about their increased risk of acute events, which can result in patient delay and serious consequences with respect to visual prognosis. These findings underscore the critical importance of integrating patient education across the entire ophthalmic care chain for myopia.

## KEY WORDS

complications, myopia, patient education, survey

## 1 | INTRODUCTION

All degrees of myopia pose a considerable risk of ocular complications (Haarman et al., 2020). These myopia-related complications are expected to rise significantly corresponding to the prevalence increase of the trait (Holden et al., 2016; Williams et al., 2015). Excessive

axial elongation of the eye increases the risk of myopic macular degeneration, glaucoma, cataract and retinal detachment, among others, leaving patients with very long eyes susceptible to severe visual impairment and blindness (Haarman et al., 2020; Tideman et al., 2016). Acute complications, such as myopic macular neovascularization and retinal detachment, require prompt

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treatment to improve the visual prognosis (Ikuno et al., 2015; Ravenstijn, Klaver, & Yzer, 2023). Previous studies have emphasized the importance of patient education in reducing patient delay, for example, in conditions like retinal detachment or age-related macular degeneration, where symptom recognition is crucial (Eijk et al., 2016; Goezinne et al., 2009; Parfitt et al., 2019). When it comes to myopia, which has a diverse range of potential complications and corresponding alarm symptoms, patient education may be even more vital for saving sight.

Our previous study explored the perspectives of both patients and ophthalmologists regarding high myopia care, which revealed that myopic patients rate the quality of information provided by the internet higher than that provided in the clinic (Ravenstijn, du Bois, et al., 2023, Ravenstijn, Klaver, & Yzer, 2023). Although the majority of ophthalmologists valued their own information exchange on myopia symptoms as adequate, most patients disagreed with that. Considering the higher risk of vision-threatening complications in myopic individuals and the importance of early intervention, optimizing patient education in myopic individuals is critical.

In this study, we performed a comprehensive investigation into current patient education in highly myopic individuals. We particularly addressed the presence, source, content and timing of the education. By reviewing these factors, we aimed to identify improvements in patient management to reduce patient delay and enhance patient satisfaction.

## 2 | METHODS

This is an exploratory, cross-sectional study that consisted of a self-reported survey conducted in highly myopic patients. Personally identifiable information was not collected. From February to March 2023, we sent out a survey to the 250 members of the high myopia patient organisation (Oogvereniging, [www.oogvereniging.nl](http://www.oogvereniging.nl)); all were highly myopic adolescents or adults, or parents

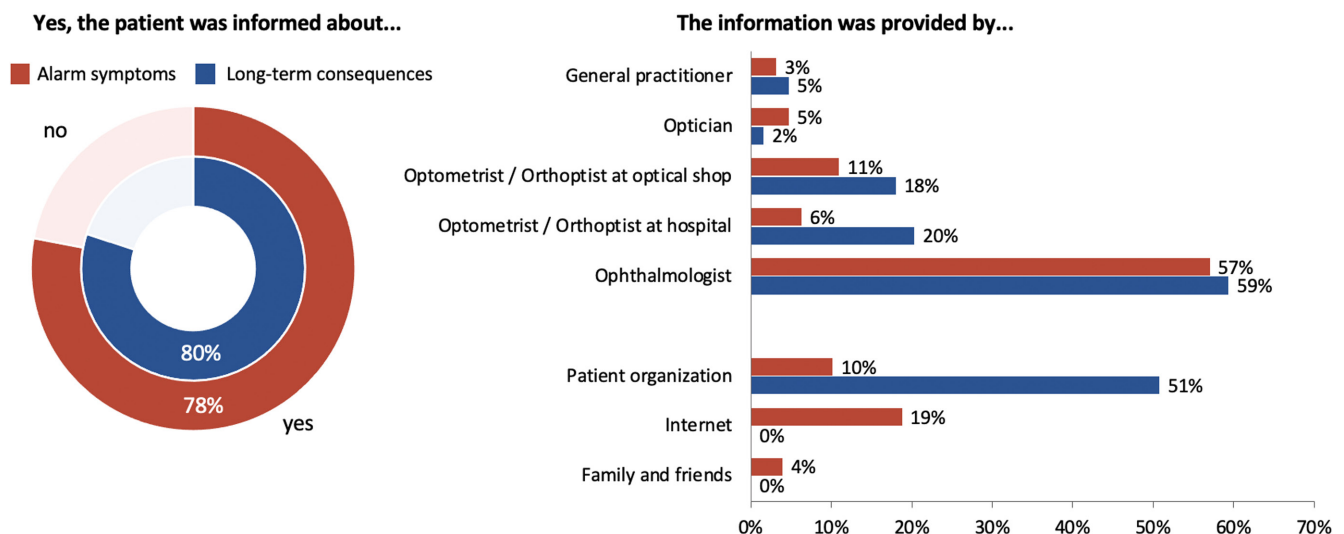
of children with progressive (high) myopia from the Netherlands. Participants were self-reported as highly myopic with a refractive error of  $\geq -6$  Diopters or less. The survey was also distributed on a Facebook page for Dutch highly myopic patients linked to the high myopia patient organisation. The survey was structured into 13 items of open and multiple-choice questions available in Dutch. Data were collected via Microsoft Forms (Microsoft.com); the survey instruments are provided in Appendix. Domains included personal experience on patient education and patients' perceptions of patient education of acute and the long-term consequences of high myopia. Data from the surveys were analysed with descriptive statistics including mean and standard deviation or proportions where appropriate. Proportions were compared using the chi-square test (Excel). A  $p$ -value of  $<0.05$  was considered statistically significant.

## 3 | RESULTS

A total of 128 persons from the Netherlands participated in this study. Of these participants, 4 (3%) were parents of highly myopic children, and 124 (97%) were highly myopic individuals of which 2 (2%) were aged  $\leq 25$  years; 7 participants (5%) were aged between 26 and 40 years; 44 (34%) between 41 and 55 years, 57 (44%) between 56 and 70 years and 14 (11%)  $\geq 71$  years.

### 3.1 | Patient education: Alarm symptoms

In this survey, 25% of the participants (32/128) had not received any education of alarm symptoms from ophthalmic care professionals. Of these 32 participants, four stated to have found the information on their own, leaving 22% of the participants (28/128) without awareness of alarm symptoms. The participants who did receive education were informed by multiple sources, with ophthalmologists as the primary source in 57% of the participants (73/128). Other sources are shown in Figure 1. In



**FIGURE 1** Patient education on acute symptoms and long-term consequences of myopia: percentages of patients who received information and the source of the information.

addition to ophthalmic care professionals, patients were also self-educated through the internet (19%, 24/128), high myopia patient organization (10%, 13/128) and family or friends (4%, 5/128).

Patient education concerning alarm symptoms included flashes of light (70%, 89/128), metamorphopsia (45%, 58/128) and sudden onset of dark spots or floaters (45%, 57/128) as shown in Figure 2. As many as 57 participants (44%) received instructions to reach out to their ophthalmologist immediately should alarm symptoms occur, while 15 participants (12%) were instructed to contact the general practitioner first. Some participants also received additional instructions such as 'contact us the same day' (30%, 39/128), 'contact us in the weekends' (9%, 12/128), 'when you contact the health care professional, also mention that you have high myopia' (16%, 21/128) and 'always contact us, even when in doubt' (27%, 35/128). Of the 100 participants who received education on alarm symptoms, 24 participants stated that they had not received any instruction on how to act in case of symptoms.

Of the 84 participants who had experienced at least one acute event at the time of the survey, 37/84 (44%) had not received any education on alarm symptoms before the first acute event. Participants who regularly visited an ophthalmologist prior to their first acute event (58%, 49/84) had received patient education on alarm symptoms before the first event in 53% of the cases (26/49). This was significantly lower in participants without regular visits to an ophthalmologist (26%, 9/35,  $p=0.002$ ). Half of the participants (42/84) acted within the same day and 18/84 participants (21%) the next day. Nine of the 84 participants (11%) contacted a healthcare professional after 2–3 days and 13/84 (15%) waited for more than 3 days. Twelve of the 13 (92%) participants who waited more than 3 days had not received education on alarm symptoms (Figure 3). Doctors delay appeared to be present as well. The ophthalmologists examined 57% (48/84) of the participants who contacted them the same day and 17% (14/84) of the participants after 1 day. In 11% (9/84), the waiting period was 2–3 days and in 15% (13/84) more than 3 days until the first appointment.

### 3.2 | Patient education: Long-term consequences of myopia

Long-term consequences of myopia were discussed with 102/128 participants (80%). The ophthalmologist was

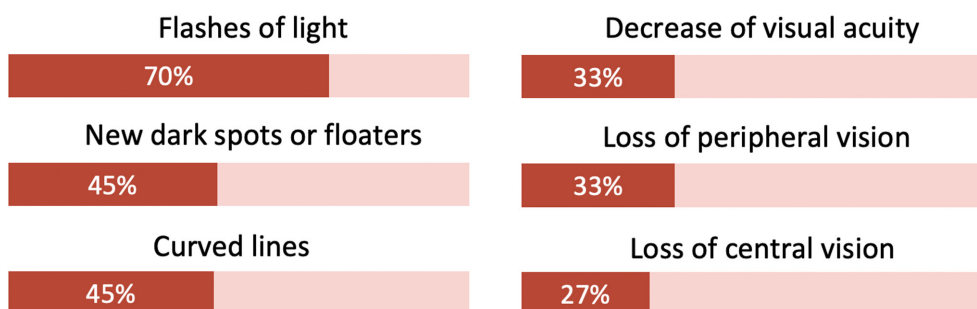


FIGURE 2 The content of the patient education on alarm symptoms.

again the most important source for patient education in 59% of the participants (76/128). Other sources are stated in Figure 1. The high myopia patient organisation was an important source of information for 51% of the participants (65/128).

Participants indicated that patient education on long-term myopic consequences should include the visual prognosis (79%, 101/128), myopia-related risks of ocular surgery (64%, 83/128), the relationship of myopia with other (ocular) diseases (51%, 65/128) and whether patients can maintain their driver's licence (52%, 66/128). In addition, patients wished to be informed about reliable web resources, patient organizations, low vision organizations (52%, 67/128) and new developments in treatments, glasses and lenses (38%, 49/128). Additionally, 52% (67/128) expressed the desire to have a basic understanding of various diagnostic ophthalmic imaging modalities and the ability to compare their outcomes with those of normal eyes. A minority of participants (9%, 12/128) indicated that they did not wish to have more in-depth information on the long-term consequences of myopia.

## 4 | DISCUSSION

This study aimed to investigate patient education in individuals with high myopia with the objective of gaining insight in current disease awareness and identifying areas for clinical improvement. We found that only 44% of myopic patients was aware of alarm symptoms prior to experiencing the first event. Furthermore, there was

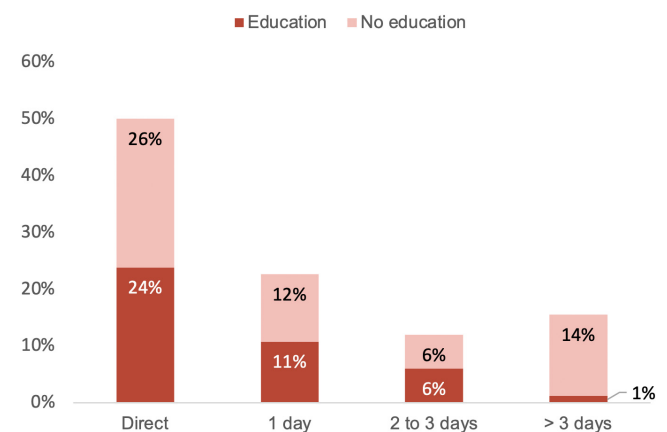


FIGURE 3 Patient delay in participants with and without patient education.

considerable variation among the participants in terms of education on alarm symptoms and on instructions how to respond. This lack of awareness can result in a detrimental patient delay with serious consequences for visual prognosis. The results of our study highlight the critical necessity of enhancing patient education to ensure timely symptom recognition and prompt medical attention.

#### 4.1 | Timing of patient education

Patient education is a powerful tool to decrease patient delay and improve clinical outcomes (Paterick et al., 2017). In this study, 78% of the participants was informed about alarm symptoms and 80% about the long-term consequences of high myopia. A previous survey of French highly myopic patients also reported that 70%, 61% and 51% of the 129 respondents had at least once been informed about the increased risk of retinal detachment, cataract and glaucoma, respectively (Gaucher et al., 2016). Nonetheless, in this surveyed population, 44% was unaware of the alarm symptoms before the appearance of the first (acute) complication which resulted in patient delay. Almost all patients (92%) who had visited the ophthalmologist later than 3 days after the first appearance of a symptom had been uneducated. However, patients who had received information had not visited the ophthalmologist on the same day that the symptom appeared. This could be attributed to either the variability in the content of the education provided or the possibility that patients had not received further instructions on how to act upon these symptoms. Implementing patient education at an earlier stage of myopia has the potential to prevent late response, which will undoubtedly increase the chance of a favourable visual outcome.

In this study, the ophthalmologist was the most important source of information on both acute symptoms as well as long-term complications. However, a large proportion of patients (42%) did not regularly visit an ophthalmologist, which may have resulted in a first consultation at the time of a complication. This may explain the perceived gap in information exchange between ophthalmologists and patients that we encountered before (Ravenstijn, du Bois, et al., 2023; Ravenstijn, Klaver, & Yzer, 2023). Other healthcare providers such as general practitioners or opticians can bridge this gap. For instance, the latter could provide patients buying glasses a leaflet that contains information on complications and on instruction how to act in case of acute symptoms. Government agencies (e.g. Ministry of Health), patient organizations and other healthcare professionals can also play a pivotal role in disseminating information on myopic complications and their associated symptoms.

#### 4.2 | Content of the patient education

Patients with myopia are known to have an up to 13 times higher risk of retinal detachment (Haarman et al., 2020). This could explain why healthcare providers tend to emphasize certain alarm symptoms, such as ‘flashes of

light’ when advising patients. For instance, 14% of the self-referred patients experiencing photopsia have a retinal tear, highlighting the diagnostic importance of this symptom (Brown et al., 2015; Hollands et al., 2009). Other important alarm symptoms such as a decrease in visual acuity or loss of central vision were only discussed with 45% of patients. With the current shift towards subspecialty care, ophthalmologists may not even be aware of risks outside their direct field of expertise, and may predominantly inform their patients about risks and long-term consequences related to their own specialty. This is a second possible explanation for the difference in information exchange perceived by patients and ophthalmologists. A well-defined myopia management protocol for the entire ophthalmic care chain will warrant more complete and timely awareness of sight-threatening symptoms in myopic persons.

In addition to creating awareness for alarm symptoms, providing patients with clear instructions on how to act upon their presentation is equally crucial. In this survey, 27% of the participants did not receive this information, which increases the risk of patient delay. The timing of response to alarm symptoms could improve with easily accessible instructions on digital or printed cards. Such an instruction card or leaflet can be distributed by any healthcare professional in the chain, for instance at the time of buying optical aids. An example of such an informative instruction card or digital site is shown in Figure 4.

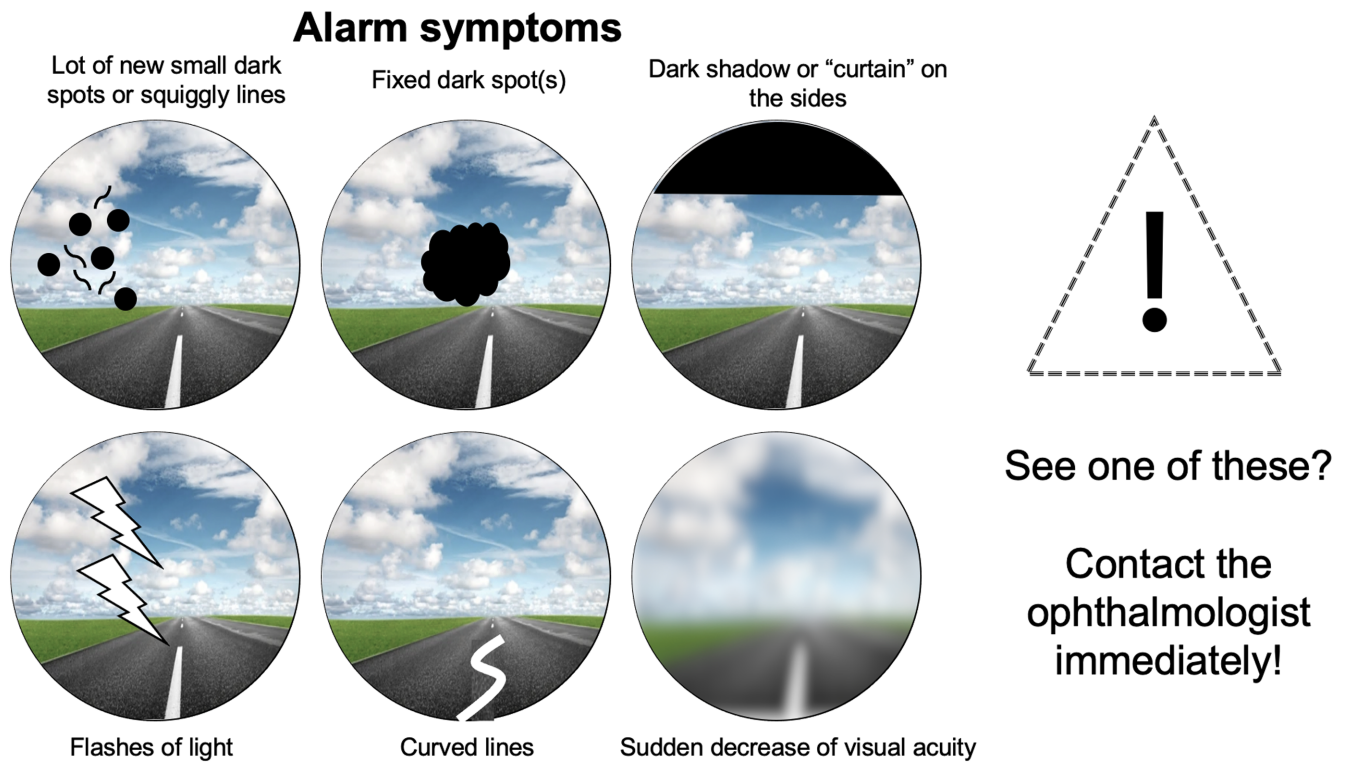
#### 4.3 | Strengths and limitations

This study had notable strengths, including a relatively large sample of participants who had experienced a first acute event. This allowed for the examination of patient education within subgroups of clinical severity. Another strength was the close collaboration with a patient organization, which helped to establish a patient-centred survey addressing the issues that they considered most relevant. Among the limitations is the potential of recall bias, for participants may have imperfectly remembered or reported the information that they received. Another possible bias is that patients dissatisfied with their myopia care provider may have been more inclined to join the patient organization and/or participate in the survey. Inclusion of a predominant group of patients who are less informed or more concerned about their health may have negatively distorted the outcome of our survey. Nevertheless, the study's substantial number of participants without complications, of individuals who received timely information, and of participants who widely vary in age and responses suggest that the study population represents highly myopic individuals well enough to generalize the outcome of our research questions to the entire patient group, at least in the Netherlands.

#### 4.4 | Perspectives

Providing information on the risks and prognosis associated with (high) myopia should be standard





**FIGURE 4** Prototype of instruction card with alarm symptoms for myopic patients.

education for individuals working in ophthalmology. In an ideal setting, all myopic individuals receive timely, consistent and personalized information on acute symptoms and long-term consequences of their ophthalmic trait and are checked by the ophthalmic care professional for understanding this information. To achieve this setting, we suggest the following improvements:

*Timing of education* plays a crucial role in creating awareness of myopia-related risks before a harmful event occurs. For all myopes, we recommend education on alarm symptoms when receiving a prescription for or buying optical aids, as all degrees of myopia increase the risk of complications (Haarman et al., 2020). To accomplish this goal, a collaborative effort from the entire ophthalmic care chain is needed, involving a broad range of healthcare professionals, government agencies and patient organizations.

To ensure both *completeness and consistency* in patient education, it is essential to establish a standardized and comprehensive approach. This involves developing informative resources, ensuring effective communication by ophthalmic care professionals and proper documentation thereof, fostering collaboration among ophthalmic care professionals and promoting continuous education of professionals to keep them abreast of the latest developments and clinical guidelines.

In addition to the previous points, recognizing the significance of *personalized* care is vital. Sharing the diversity of lessons learned from the clinic with the entire research community will stimulate studies into the wide range of factors that contribute to the development and progression of myopia and myopic complications. Setting up a large multicentred database of patient profiles, myopic complications, and visual outcomes could

be a valuable starting point for comprehensive data-driven investigations. This will foster a deeper understanding of each patient's disease course, facilitating the development of patient-centred care.

Though it might initially increase the workload of ophthalmic care professionals, addressing the current shortcomings in patient education and implementing the recommendations following from our study will elevate high myopia care to a much-needed higher level.

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#### CONFLICT OF INTEREST STATEMENT

None of the authors have any potential sources of conflict of interest.

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## APPENDIX

### 1. I complete this questionnaire as

- Parent or caregiver of child(ren) with myopia
- Adult with myopia

### 2. Age of the participant

- 24 years or younger
- 25–40 years
- 41–55 years
- 56–70 years
- 71 years or older
- Patient education on alarm symptoms

### 3. Did you receive the education of alarm symptoms before the occurrence of a first complication?

- Yes
- No

### 4. Which alarm symptoms were discussed with you?

- Multiple answers are possible.
- Flashes of light
- Decrease of visual acuity
- Sudden onset of floaters or dots
- Vision loss at the periphery
- Vision loss at the centre
- Metamorphopsia/curved lines
- Other, namely \_\_\_\_\_

### 5. Who educated you on these alarm symptoms?

- Multiple answers are possible.
- I did not receive any information about alarm symptoms up to date.
- General practitioner
- Optician
- Optometrist or orthoptist at optical shop
- Optometrist or orthoptist at the hospital
- Ophthalmologist
- Patient organisation
- Internet
- Family and friends

### 6. Did you receive additional instruction in case of alarm symptoms?

- Multiple answers are possible.
- No
- Yes, to call the general practitioner
- Yes, to call the ophthalmology department of the nearest hospital
- Yes, to call the same day/within 24h
- Yes, to mention your highly myopic in combination with your symptoms
- Yes, to also call in the weekends
- Yes, to always call even when in doubt.
- Yes, and the instruction were the following

### 7. Did you experience an acute problem before? If not, continue to question 12.

- Yes
- No

8. When you first experience an acute symptom, how soon did you contact a medical professional or ophthalmic care professional?

- Direct
- One day later
- Two days later
- Three days later
- More than 3 days later

9. How many days after you contacted a medical professional or ophthalmic care professional until you could visit the ophthalmologist?

- Direct
- One day later
- Two days later
- Three days later
- More than 3 days later

10. Did the ophthalmologist told you to reach out sooner the next time?

- Yes
- No

11. Were you under regularly check-ups with the ophthalmologist at the first time of the acute problem?

- Yes
- No
- Patient education on long-term consequences of myopia

12. Who informed you about the long-term consequences of myopia?

- Multiple answers are possible.
- I did not receive any information about long-term consequences up to date.

- General practitioner
- Optician
- Optometrist or orthoptist at optical shop
- Optometrist or orthoptist at the hospital
- Ophthalmologist
- Patient organization
- Internet
- Family and friends

13. On which topics would you like more information?

- Risks of visual impairment and blindness
- Night blindness
- Loss of peripheral vision
- Loss of central vision
- Development of cataract in myopic individuals
- Ocular surgery in combination with high myopia
- Ocular medication
- Interaction of myopia with other (ocular) diseases
- Driver's licence
- Advice to participate in certain activities, such as playing a brass instrument, riding a rollercoaster or heavy weightlifting.
- Interpretation of diagnostic tools and imaging modalities
- Information about vision aid tools and low vision institutes
- Update on future glasses and lenses in myopia management
- Other, namely \_\_\_\_\_