The Research Priorities of People with Visual Impairments in the Netherlands

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Structured abstract: *Introduction:* Despite the relatively high prevalence and challenges of visual impairments, limited funding is available for ophthalmologic research in the Netherlands. The research needs of people with visual impairments could aid the ophthalmological research community to optimally distribute research resources. The objective of the study presented here was to identify daily life problems, concerns, and wishes for future research from people with ophthalmological disorders, visual impairments, or deafblindness in order to set a research agenda that provides directions for future ophthalmology research. *Methods:* A four-phase participatory research approach was carried out using mixed methods to stimulate needs-articulation. Eight focus group discussions, seven feedback meetings, and seven interviews were organized, in which 89 consumers were consulted. Surveys to prioritize the topics were developed for both the medical and sociopsychological topics, which were completed by 784 and 631 respondents, respectively. *Results:* For the medical research agenda, research directly aimed at the cause of the ophthalmological disorders was considered more important than research aimed at improving quality of life. The themes "new and regenerative medicine," "cause and disease mechanism," "prevention and diagnosis," and "improvement of current treatments" were prioritized as high. For the sociopsychological agenda, needs concerning the "improvement of technologies for people with visual impairments" and "navigation, orientation, and accessibility of public space" were considered top priorities. *Discussion:* The identified research needs were relatively uniform across different consumer groups, providing opportunities for joint action. The research agenda included themes that can be taken up by "traditional" ophthalmological research, more broadly defined health care–related research, and more policy-influencing strategies. *Implications for practitioners:* The research needs could help researchers and policymakers in ophthalmology and visual impairment research to guide their research focus and legislation priorities.

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Considering the high prevalence and both physical and mental considerations related to visual impairments (Chia et al., 2004; Nyman, Gosney, & Victor, 2010; Ramrattan et al., 2001), the field of ophthalmology in the Netherlands is relatively small when measured by allocated research resources (S. Imhof, personal communication, March 28, 2015), yet of a high academic standard (Guerin, Flynn, Brady, & O'Brien, 2009). Underlying reasons for this lack of funding are possibly the invisibility of the disability, the fragmented consumer community, and the high age of onset of most ophthalmological diseases. Given this limited funding, optimal distribution of research resources is of vital importance. A research agenda—a list of relevant topics in a specific field—can be a helpful tool in providing direction for future ophthalmology research, and can be of value to research institutes and funding agencies (Pittens, Elberse, Visse, Abma, & Broerse, 2014).

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Our study investigated the research needs of people with a range of ophthalmological disorders, including visual impairments or deafblindness. It aimed to provide the research community with important input to such an agenda. According to Caron-Flinterman, Broerse, & Bunders (2005a) and Oliver et al. (2001), individuals possess a unique perspective on their own disabilities, since they deal with the consequences of disability on a daily basis. In addition, such individuals benefit most directly from the outcomes of scientific research and, therefore, have the moral right to be involved in the decision-making process concerning their impairments (Goodare & Smith, 1995; Popay & Williams, 1996). Last, involvement of people with disabilities in a research agenda setting could increase the legitimacy of research (Collins & Evans, 2002; Williamson, 2001). For these reasons, the involvement of medial patients in setting research agendas has already taken place in the Netherlands; for instance, on burns (Broerse, Zweekhorst, van Rensen, & de Haan, 2010); asthma, chronic obstructive pulmonary disease (COPD), and rare lung diseases (Caron-Flinterman, Broerse, Teerling, & Bunders, 2005b; Elberse et al., 2012b); and, at a more general level, medical products (Elberse, Pittens, de Cock Buning, & Broerse, 2012a).

People with visual impairments have sporadically been consulted about their opinions on scientific research topics and

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This research was financially supported by the Programmaraad Visueel Gehandicapten [Program Council for the Visually Impaired] of the Netherlands. The authors are grateful to the members of the project group and the advisory board for their support and critical reflections during the research. We thank the Eye Association Netherlands and the Macular Degeneration Association for their assistance in the dissemination of the focus group discussion invitations, the questionnaire, and the final report. Above all, we are indebted to all consumers who participated in this research on a voluntary basis. None of the authors has any financial or personal relationships with other people or organizations that could inappropriately influence their work.

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conduct (Duckett & Pratt, 2001; Elberse et al., 2012a; Sight Loss and Vision Priority Setting Partnership, 2013). The aim of this article is, therefore, to identify daily life problems, concerns, and wishes for future research from people with vision loss in order to set a research agenda that provides directions for future ophthalmology research.

Methods

Research activities were carried out along the lines of the Dialogue Model (Abma & Broerse, 2010). This approach is one of two available research agenda–setting methodologies. The Dialogue Model is designed and validated in the Netherlands; the other agenda-setting strategy, developed by the James Lind Alliance (Cowan & Oliver, 2016), is mainly in use in the United Kingdom. Both approaches can be interpreted as the operationalization of the first component (topic generation) of the Patient-Centered Outcomes Research Institute (PCORI) framework, which focuses on the broader issue of research gap identification and prioritization (Wald, Leykum, Mattison, Vasilevskis, & Meltzer, 2014). In contrast to the James Lind Alliance approach, the Dialogue Model is explicitly based on the daily life experiences, problems, and concerns of the target community. This subsequently aids in the identification of their research wishes. These experiences aid in contextualizing the research themes that result from the collaborative and consultative endeavor.

The Dialogue Model is based on a responsive methodology and the interactive learning and action approach (Abma & Broerse, 2010; Broerse, Elberse, Caron-Flinterman, & Zweekhorst, 2010). It is grounded in six principles: active engagement of patients, favorable social conditions, respect for experiential knowledge, dialogue, emergent and flexible design, and process facilitation. The Dialogue Model has been validated as an effective tool for investigating and explicating stakeholders' opinions regarding the setting of research agendas (Abma & Broerse, 2010; Abma, Pittens, Visse, Elberse, & Broerse, 2014; Caron-Flinterman et al., 2005; Elberse et al., 2012b; Nierse, Abma, Horemans, & van Engelen, 2012). It was originally comprised of six phases, of which the first four were executed in the project presented here: exploration, consultation, priority setting, and agenda setting.

A project group was established, consisting of eight consumer representatives and the authors of this article. The consumer representatives in the project group were both volunteers and employees of the Eye Association Netherlands (EAN) and the MD (Macular Degeneration) Association, including the director and president of the respective associations. The principal task of this project group was to discuss all substantive decisions during the course of the project. In addition, an advisory board comprising five leading experts in ophthalmology and visual impairment research and care was formed to provide the project group with advice on the course of action during the project and to reflect on intermediate results. Advisory board members were the president and former president of the Dutch Ophthalmic Society, the president of Optometrists Association Netherlands, and two board members of Visio and Bartiméus, respectively, two leading

Table 1
Participants in focus group discussions, feedback meetings, and interviews in consultation phase.

Group	Data collection moment	Number of participants
Glaucoma	FGD	11
	FBM	3
Macular degeneration	FGD	12
	FBM	3
Retinal disorder (excluding macular degeneration)	FGD	8
	FBM	3
Deafblindness	FGD	4
	FBM	2
Parents of children with visual impairments	FGD	6 + 1 grandmother
	FBM	3
Blind people, mixed etiology	FGD	10
	FBM	2
People with partial visual impairment, mixed etiology	FGD I	8
	FGD II	4
	FBM	2
Younger (aged 30–38), employed people with visual impairments (partial or blind)	Individual interviews	3
Corneal disorders	Group interview	3 (board members of Cornea Patients Association Netherlands)
Retinopathy of prematurity	Individual interview	1
Total	All collection methods	89

FGD = focus group discussion; FBM = feedback meeting.

rehabilitation organizations in the Netherlands.

DATA COLLECTION

Exploration phase

Six representatives of people with visual impairments were interviewed to provide insight into the community. Considering the heterogeneous nature of the target group, special attention was paid to the representation of major relevant ophthalmological diseases and several degrees of severity of visual impairment. The interviewees were members of EAN, which represents people with retinal disorders and glaucoma, and parents of children with visual impairments; and the MD Association. The interviews comprised two main parts: an initial consultation of daily life problems, concerns, and research wishes of the target population the interviewees represented; and social conditions and tips to be taken into account for the next phase of the research project.

Consultation phase

Guided by input from the interviews, eight focus group discussions, seven feedback meetings, and four additional semistructured interviews were organized to further identify daily life problems, concerns, and research wishes of the target population. A total of 89 participants took part (see Table 1). Focus group discussions were assigned to a major ophthalmological disease (glaucoma, macular degeneration, retinal disorders, and deafblindness), a specific target group (parents of children with an ophthalmological disease), or severity of the visual impairment (blindness or low vision).

Focus group discussions lasted 2.5 hours and were organized at a centrally located and accessible meeting venue in Utrecht, the Netherlands. Transportation assistance from the train station to the meeting venue was provided. Participants were recruited via EAN and the MD Association. In the process of setting a research agenda for a target group, it is important to first investigate daily life problems and concerns and then to translate these into research topics (Abma & Broerse, 2010). To this end, the focus group discussion design comprised the following parts: introduction; identification of daily problems of individuals; identification of concerns; and proposing solutions with respect to scientific research to address these problems and concerns. The resulting topics were first classified into three categories—medical, paramedical (relating to devices), or sociopsychological—and then, after noting the small number of paramedical issues, into two categories (medical and sociopsychological). Any questions to which scientific research could not contribute were noted but not further discussed.

Subsequently, a series of feedback meetings were held. Participants, who were members of EAN and MD Association, were invited as consumer-representatives and had not taken part in the focus group discussions. Participants in the feedback meetings received the summary of the focus group discussions in advance and were asked to reflect upon the findings. The composition of the focus group discussions, recognition of the discussions, and any underexplored topics were discussed.

After the focus group discussions and feedback meetings, additional interviews ($N = 7$) were held to include the perspectives of under-represented consumer groups. Respondents were recruited via purposeful sampling and were interviewed individually or in a small group using an interview guide comparable to the focus group discussion setup.

Priority setting phase

Questionnaires were developed for the medical and sociopsychological topics, which were clustered according to themes: seven themes for the medical survey and six themes on the sociopsychological survey. Respondents were asked to allocate a gold, silver, or bronze medal to the research topics they considered most important. Medals were awarded within each theme and across themes within the particular questionnaire. Respondents were given the option of adding uncategorized topics to the questionnaire at the end. These were, however, not prioritized. The medical and sociopsychological questionnaires were linked, so people could complete both surveys by filling in their personal details (age, gender, age of onset and severity of visual impairment, type of ophthalmological disease, and membership in a consumer association) only once.

The questionnaires were publicly available digitally via the online tool Survey Monkey and on paper. Advice was sought on an appropriate print font and format for the paper version of the survey. Adjusted formats were available upon request. The online questionnaires were pretested by people with visual impairments using various computer software programs (JAWS and Supernova, providing braille and speech support) to check for compatibility. Personal assistance was not proactively offered due to workload constraints, but was offered when respondents indicated they were encountering problems with the format. Recruitment of respondents took place via several communication channels of the EAN and the MD Association, such as social media, mailing, and an advertisement during an annual visual impairment consumer fair. The running time of the survey was four months. Halfway through the term, additional calls were sent out for people with deafblindness, nystagmus, corneal disease, and cataracts to increase their response level in the survey. In total, 566 people completed both questionnaires, with 218 responding to the medical questionnaire and 66 the sociopsychological questionnaire only.

Agenda-setting phase

The most prioritized research topics were discussed during a dialogue meeting with 32 consumer representatives and stakeholders from various ophthalmological health care, research, and funding authorities in the Netherlands. The goal of this meeting was to present and discuss the preliminary outcomes and to create support for further implementation of the research agenda by different stakeholder organizations.

DATA ANALYSIS

All focus group discussions and interviews were audiotaped, transcribed verbatim, and summarized. Summaries were sent to all participants for member check. Using the analysis software MAXQDA, thematic content analysis of the transcripts resulted in a list of daily problems and concerns. A problem analysis was carried out to unravel the relationships between these daily problems and concerns by identifying both explicit (extracted from the transcripts) and implicit (interpreted by the researchers) relationships.

The questionnaire was analyzed quantitatively by awarding each gold, silver, and bronze medal with three, two, and one points, respectively. Research topics were prioritized across themes by an equal contribution of the awarded points within the theme, and for the awarded points of the theme under which the topic fell. This resulted in a list of all research topics, irrespective of theme, of declining priority. As the points quantify the priorities artificially and cannot be verified either between or within respondents, a classification system consisting of a high, medium, and low priority range was decided upon. Demarcation between high, medium, and low priority was determined by manually selected cutoffs, which resulted in two top-priority classes of nine medical and nine sociopsychological research topics. To measure differences between the various groups of respondents, stratification analysis of the highly prioritized research topics was performed between ophthalmological disease, severity of the visual impairment, age, gender, and membership in a consumer association using an unpaired two-tailed t-test in SPSS with a Bonferroni correction to adjust for multiple testing.

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ETHICAL CONSIDERATIONS

The study respected privacy and confidentiality. It did not need the approval of an accredited Dutch medical research ethics committee, since it did not concern medical research or any form of invasion of the participants' integrity, and anonymity was guaranteed. The declaration of Helsinki was applied to the work with participants in interviews and focus group discussions.

Results

We first describe the causal analysis of daily life problems and concerns. Second, we present the medical and sociopsychological research agendas. Last, the results of the stratification of research priorities are given.

CAUSAL ANALYSIS OF DAILY LIFE PROBLEMS AND CONCERNS

Figure 1 presents a simplified version of the problem analysis on daily life problems and concerns, as identified in the consultation phase. A reduced quality of life is placed at the top of the analysis. The rest of the diagram illustrates the origins of this problem, which relate to facets of daily life and the negative feelings about life in general that experiencing such problems can generate.

In this paper, two examples of the problem analysis are elaborated upon: reduced mobility; and problems with social interaction, fatigue, and acceptance of impairment. These examples have been selected out of many because they relate to the most pressing research topics prioritized by the target population.

Reduced mobility

Almost all participants in the focus group discussions pointed out that reduction in mobility was caused both by the visual impairment itself and by the norms of a visually oriented society. According to an anonymous participant in the focus group discussion for visually impaired people:

> People tend to work visually, with icons. Using GPS, people can use maps, use Google maps, or Google Earth. That's perfectly fine for those who see it, but a discrepancy arises between what people see and what they express verbally.

Society provides more complications for people with visual impairments: a chaotic organization of public space, unreadable public transport information, inaudible broadcasting systems, and poorly visible sidewalks are but a few of the hurdles these people face when moving about outside (see Figure 2 for a more extensive overview). These factors disturb a person's ability to orient him- or herself, cause fear of losing balance, and cost time for travel preparation, thus hindering mobility. Reduced mobility in turn reduces an individual's independence, causes social isolation, and reduces the overall enjoyment of life, according to a young, employed visually impaired person we interviewed:

> One of the main troubles is the effort it takes to get somewhere. . . . When you go out on your own, which I do regularly, it's tight and sometimes

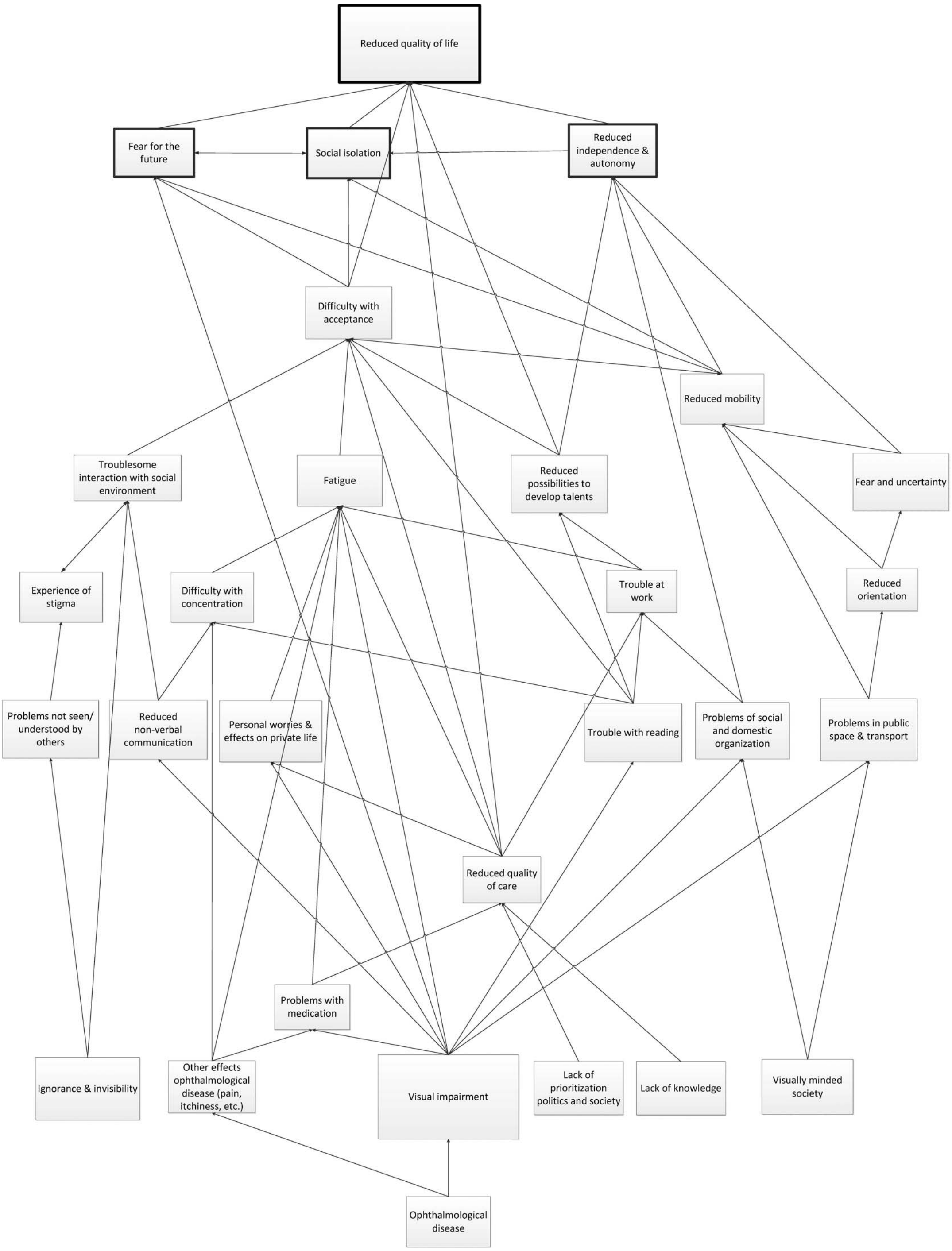

Figure 1. Simplified version of the problem analysis.

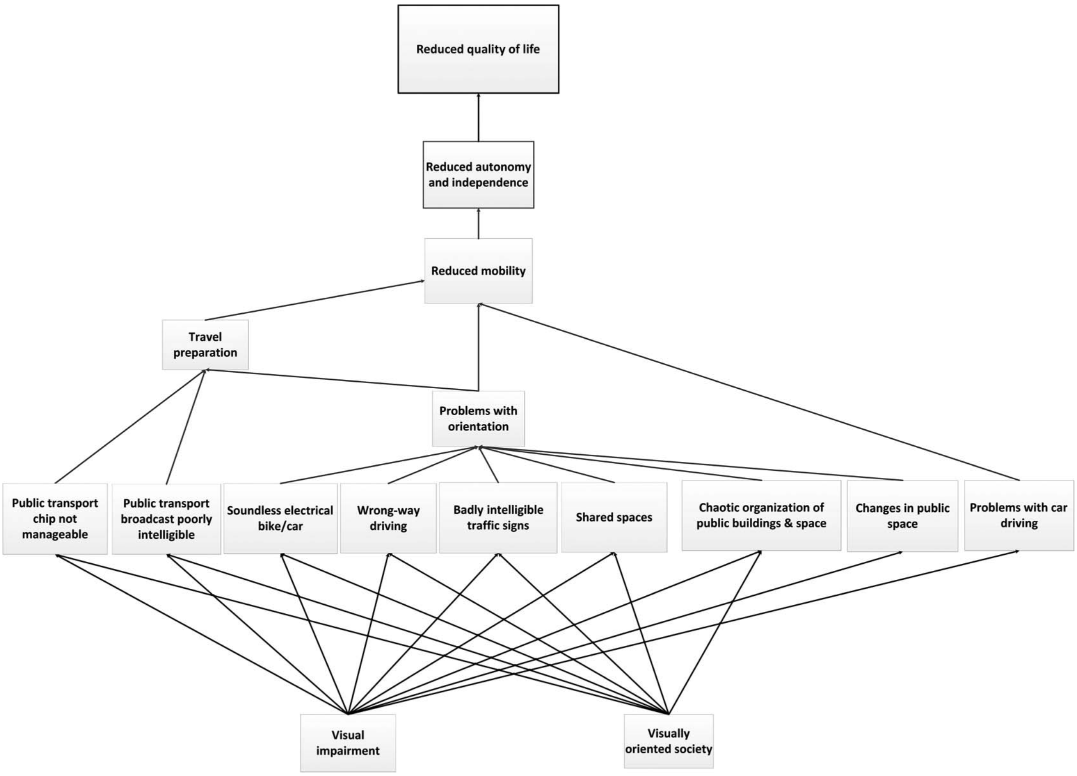

Figure 2. Overview of complications for people with visual impairments.

> frightening. And it requires more organization. From train station to train station is quite fine, but you have to trust people, at which I'm improving. . . . But when you need to get to a building by yourself: you need to be accompanied, you need to arrange that. . . . It requires more organization. I haven't managed on my own yet. That's my main trouble.

Problems with social interaction, fatigue, and acceptance of the visual impairment

Many respondents indicated that people with vision loss often face incomprehension and even stigmatization due to the lack of obvious visible symptoms of visual impairments and ignorance in the general population about the consequences of ophthalmological disorders. In addition, in social interactions, eye contact and nonverbal communication are partly lost, causing people to have difficulty building up friendships. Spontaneity and communication are hindered. For example, it can be hard to recognize people at parties and on the street, according to a participant with retinal disorders who said the following in a focus group discussion:

> When there's a party, for example, with some people you know and others you don't, then it's hard to get in touch. Where is whom? Simply because I don't recognize the faces anymore. When I've talked to someone and later someone addresses me, I'm afraid to tell the same story over

> again. Because I don't remember to whom I talked anymore because I don't recognize him. . . . Sometimes when I'm in doubt, I keep [my mouth] shut.

In the focus group discussions, many respondents said that they experience fatigue as a result of the difficulties faced in social life, disturbed biorhythms, side-effects of medications, or simply because all daily routines require more attention:

> You wake up in the morning, you have to search for your clothes. You drop your toothpaste, you can't simply look for it and pick it up—no, you have to search the entire floor. . . . Everything requires more energy.

Moreover, for many participants, the acceptance of their vision loss is hampered in multiple ways by: reducing their self-esteem, making it more difficult to find a partner, and causing fatigue. This difficulty in accepting the vision loss reduces the quality of life, directly and indirectly, through social isolation and fear for the future.

MEDICAL AND SOCIOPSYCHOLOGICAL RESEARCH AGENDAS

Table 2 lists the highest prioritized research topics for the medical and sociopsychological research agendas. Concerning the medical research agenda, many people would like more resources and attention to be allocated to tackling the cause of their problem, the ophthalmological disorder, rather than improving the quality of their life through other means. The theme "new and regenerative medicine" gained 23% of allocated points, resulting in many topics under this theme being listed high on the medical research agenda. Also the themes "cause and disease mechanism," "prevention and diagnosis," and "improvement of current treatments" were prioritized high with, respectively, 21%, 21%, and 20% of the allocated points.

On the sociopsychological research agenda, much attention was paid to the "improvement of technologies for people with visual impairments," 32% of the allotted points. Sociopsychological research should, according to visually impaired people, mainly focus on improving their self-sufficiency. The theme "navigation, orientation, and accessibility of public spaces" corresponds directly to the troubles in mobility that were mentioned in the focus group discussions, and yielded 20% of the awarded points.

In response to the open question as to whether respondents missed any topics on the survey, 20 respondents added a question regarding the impact of a visual impairment on a family setting to the sociopsychological agenda. However, considering the low importance given to the theme "psychosocial acceptance" in general (8%), it is doubtful whether this topic would have been prioritized highly.

STRATIFICATION OF RESEARCH PRIORITIES

The research priorities were stratified based on type of ophthalmological disease, severity of the visual impairment, age of onset of the visual impairment, gender, age, and membership in a consumer association. Based on this stratification, it appears that the heterogeneously

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Table 2
The highly prioritized topics, including associated themes.

Themes	Topics
Medical research agenda	
New and regenerative treatments	Stem cell therapy that can replace lost eye tissue; *stem cell therapy* means transforming one's own cells to replace lost tissue Gene therapy to make the eyes function properly again; *gene therapy* means changing the genetic code of defective cells to make them function properly again Replacement or repair of the retina
Prevention and diagnosis	The influence of diet and lifestyle to avoid my ophthalmological disorder, or slowing or stopping its progression Heritability research on my ophthalmological disorder to predict more accurately whether (grand)children of people with my ophthalmological disorder have a greater chance of developing my ophthalmological disorder Improvement of eye tests and visual field examinations to decrease the burden for patients and to improve reliability
Cause and disease mechanism	Course and progression of ophthalmological disorders The influence of an early diagnosis on the development of the ophthalmological disorder Improvement of current treatments Prevention of serious complications during eye surgery
Sociopsychological research agenda	
Improvement of technologies for people with visual impairments	What mainstream technologies are directly accessible and usable for people with visual impairments? Simple method to make product information on packaging accessible (product name, best-before date, or the list of ingredients) Improvement of a technique to convert printed and written texts (including course material) into an accessible format by and for people with visual impairments The adjustment of mainstream technologies (like Google Glass, smartphones, tablets, indoor GPS, and the like) to make them accessible for people with visual impairments to replace (expensive) devices Creation of barrier-free (domestic) appliances that can be controlled with applications ("apps") that can be connected to various devices to avoid such appliances needing to be manually adjusted for people with vision loss Development of auditory-tactile information functions for everyday consumer appliances (coffee makers, washing machines, microwaves) so they include tactile information and their functions can be controlled by voice
Navigation, orientation, and accessibility of public spaces	Improvement of GPS technology so it also indicates environmental information such as signposts, trees, and other obstacles in public spaces. Could also be used to find one's way indoors (in buildings) Making the payment system for public transport in the Netherlands user-friendly for people with visual impairments
Improvement of health care and rehabilitation care	Improvement of the system of coordination, delivery, and reimbursement for devices that takes into account progressive vision loss and changing needs

composed group of respondents prioritized research topics relatively homogeneously. Top priorities varied little across groups of respondents.

No significant differences were found regarding stratification of the results according to gender and severity of the visual impairment. Age was a factor of little influence in prioritization even though, in accordance with the aging consumer population, a relatively older age group filled out the survey. The survey was filled out by a relatively small group of nonmembers of a consumer organization, who prioritized research topics almost identically to members.

Age of onset proved to be a significant factor for some medical and sociopsychological research themes. Respondents who experienced visual impairment at a younger age tended to prioritize research themes regarding revalidation and reintegration schemes and employment opportunities. Also, they were more interested in genetic factors influencing the onset and progression of their ophthalmological disorder. Respondents with a later age of onset prioritized retaining social support structures for people who became visually impaired at a later age, and they were interested in the influence of an early diagnosis on the progression of the disease. This latter topic was also highly prioritized by sighted people who had an increased risk of developing visual impairments.

When results are compared between various ophthalmological diseases, some of the highly prioritized topics can be explained by the nature of the disease. The application of glaucoma medication is, for example, considered a burden for people with glaucoma, which translated to a greater desire for technologies to apply the medication more purposefully and less frequently. Similarly, the retina is unscathed for people with glaucoma, hence they do not give priority to research considering the replacement or repair of this tissue, while this is a highly prioritized topic for people with a retinal disorder. Diagnostics to detect the specific combination of deafness and blindness are highly prioritized solely by people with deafblindness. Other prioritization differences cannot be explained as straightforwardly.

Discussion

This research agenda reflects the daily life problems and concerns and wishes for future research of people in our target group, and thus provides helpful directions for future ophthalmology research.

Considering the perceived heterogeneity of the consumer population in terms of daily life problems associated with the various ophthalmological diseases, which was repeatedly expressed during the exploration phase and several project group meetings, the homogeneity in prioritization of the research topics was surprising. On the medical research agenda, a large portion of the highly prioritized topic list was identical for respondents of different ages, gender, age of onset, and severity of the visual impairment. Most differences in prioritization by ophthalmological disease can be explained readily, given the etiology or symptoms of a particular disease. The sociopsychological research agenda was even more homogeneous among groups of respondents. Only stratification by age yielded slight differences on this agenda. For example, older people prioritized research into the social development, living situation, and preservation of the social network of people who have become blind at an older age. Although the differences in the balance of prioritizations should be acknowledged, the homogeneity of the remaining topics emphasizes the need and the possible departures for joint consumer action. Thereby, this research agenda does not

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only offer the ophthalmological research community insight into the wishes and needs of their clientele, it also provides a fruitful common ground for cooperation between various consumer groups. This outcome is comparable to the investigation of consumers' priorities in medical products and for asthma, COPD, or rare lung diseases (Elberse et al., 2012a, 2012b). In both cases, a diverse group of consumers were able to provide useful input for an advisory process, and the research needs they formulated also showed much homogeneity.

In general, research topics can either be mapped directly for the problems or concerns experienced by the participants, or they can contribute at a more general level to solving the underlying cause of discomfort reported by participants. Topics on the sociopsychological research agenda generally aimed at finding solutions for specific problems. For example, in regard to problems with orientation in public spaces, the Global Positioning System (GPS) technology could be improved so that it also indicates environmental information such as the location of signposts, trees, and other obstacles in the community. Similarly, the desire to improve the coordination, delivery, and reimbursement for medical devices, considering a person's changing needs as vision diminishes, can be readily explained in light of the frequently burdensome procedures people spoke about in applying for these devices. On the other hand, the medical research agenda yielded topics to investigate on a long-term basis, aimed at primary, secondary, and tertiary prevention and cure rather than solving people's current daily life problems. For example, research into the inheritability of an ophthalmological disease can be considered highly relevant to prevent a consumer's child or grandchild from inheriting the disease, but it cannot be mapped directly to the daily problems experienced by a person currently experiencing the impairment. Rather, it relates to a concern the target population has for future generations. This dichotomy illustrates the importance of collecting daily life problems as well as concerns of the target population and the research questions people have, since the results are complementary to one another.

An interesting high-priority topic on the medical research agenda is the wish to allocate more research resources to the influence of diet and lifestyle on the progression and prevention of ophthalmological diseases. For this topic, the divergence in research needs and approaches between consumers and researchers are illustrated. During the reflection meeting, consumers expressed the need to have the sense separated from the nonsense in this area. Although they want to combat their feelings of helplessness by actively fighting their disease, lifestyle advice they receive from various healthcare professionals is often vague or even contradictory. Researchers present at the meeting acknowledged the need for more research in this area, while indicating the methodological challenges associated with large epidemiological studies on food and lifestyle.

The EAN and the MD Association have recently appointed a research coordinator to plan the implementation of the research agenda. A challenging task for this coordinator will be the alignment of the research agenda with current research practices in the Netherlands and abroad, since its topics suggest the need for a broad scope of research and policy-related strategies. For example, research into the improvement of eye tests and visual field examinations to decrease the burden on consumers and to improve reliability can be aligned with research goals by optometrists, while research into the replacement or repair of the retina can be a challenge taken on by eye surgeons. For some topics, predominantly those listed on the sociopsychological agenda, strategies other than research may be more applicable to reach the goals set by the consumer population. For instance, influencing policy through lobbying could help strengthen the EAN and MD Association's stand to improve user-friendliness of the payment system in public transport in the Netherlands for people with visual impairments. The subsequent components of the Wald et al. (2014) PCORI framework of research prioritization (gap analysis in systematic review, value of information analysis, and peer review) can be recommended to guide the implementation process of this research.

STRENGTHS AND LIMITATIONS

Due to the perception of heterogeneity of the target population, it was crucial to secure the support of the consumer community throughout the course of this research. Several inclusion strategies analogous to Elberse, Caron-Flinterman, & Broerse (2011) were employed. Focus group discussions were organized for homogenous groups of participants in terms of etiology and symptoms of ophthalmological disease, and the survey results were analyzed with explicit attention to the variables that could skew the results.

The agreement on the problems and concerns from the focus group discussions, expressed during the various feedback meetings, suggested that data saturation was achieved. Moreover, no new major topics arose during additional interviews with younger people and employed visually impaired people who were under-represented in the focus group discussions.

The survey yielded a generalizable view of the research priorities set by people in the target group, with some notable exceptions for some ophthalmological diseases explicitly expressed. The large attendance at the various consultation meetings and the high response rate to the survey indicate the urgency of a research agenda from the perspective of consumers in the field of ophthalmological disorders and visual impairment.

Two previous studies have identified research themes for visual impairment from a consumer perspective (Duckett & Pratt, 2001; Sight Loss and Vision Priority Setting Partnership, 2013). The results of this research agenda correspond generally to their findings. In the study by Duckett and Pratt (2001), a sample of 37 people from Scotland with visual impairments mentioned broad issues related to, among others, access to the environment; access to information, attitudes and stigma; the need for collective action to raise political awareness and improve allocation of resources; and financial and social support needs as themes to be investigated in visual impairment research. The James Lind Alliance (Sight Loss and Vision Priority Setting Partnership, 2013) has consulted consumers, relatives or carers, representatives of an organization, and eye health professionals to set distinct research agendas for different ophthalmological diseases. This study predominantly focused on medical topics, since respondents were asked what question or questions about the prevention, diagnosis, and treatment of sight loss and eye conditions they would like to see answered through research. Based on ophthalmological disease, all research topics were allocated to a category, and the research agendas were analyzed separately. Rather than merely extending the research of Duckett and Pratt (2001) and the Sight Loss and Vision Priority Setting Partnership (2013) to the Dutch context, we have broadened the scope of this research to both sociopsychological and medical research topics, and to a higher level of specificity of the research topics. Compared to the study by Duckett and Pratt (2001), we included a larger and more diverse population of people with visual impairments, ophthalmological disorders, or deafblindness in our study. Also, in contrast to the study by the Sight Loss and Vision Priority Setting Partnership (2013), we have actively pursued integration of the research themes across different ophthalmological diseases, since respondents indicated the need to join forces in ophthalmological research and to allow for more multidisciplinary research approaches. In addition, our data is refined by an in-depth analysis of the problems and concerns that emerged as a result of these discussions regarding visual impairments and ophthalmological diseases.

Conclusion

The study presented here has identified the daily life problems and concerns and wishes for future research of people with ophthalmological disorders, visual impairments, or deafblindness, with the aim of setting a research agenda for ophthalmology research. The list of highly prioritized topics is relatively uniform across different consumer groups, providing opportunities for joint action. The research agenda includes themes that can be taken up by "traditional" ophthalmological research, more broadly defined health care–related research such as studies concerning implementation, and more policy-related strategies. Further, in-depth study of these topics—for example, by following the subsequent components of the PCORI-framework—will indicate the most effective route for the EAN and the MD Association to achieve a more consumer-centered research program on cures and care for affected people in the Netherlands.

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