

# ARTICLE SCIENTIFIQUE

A participatory research to design a survey providing a portrait of the life of people with visual impairments

## OBJECTIF

- ⇒ Cet article illustre un exemple de recherche participative basée sur une étude réalisée à l'UR DIPHE (projet Homère)
- ⇒ Il vise à montrer le processus de conception d'une enquête en ligne visant à dresser un portrait de la vie des personnes déficientes visuelles
- ⇒ Étude pilotée par le laboratoire DIPHE en collaboration avec l'équipe Technologies, Handicaps Interfaces Multimodalités (THIM) du laboratoire de recherche Cognitions humaines et ARTificielles (CHArt), Médialis/Autonomii et VAA Conseil

## METHODE

- ⇒ Création d'un questionnaire de recherche avec la méthode Delphi
- ⇒ Processus de conception participative : participation à la création des personnes déficientes visuelles, proches, professionnels et chercheurs

## RESULTATS

- ⇒ Les personnes déficientes visuelles peuvent être parties prenantes de la recherche qui les concerne
- ⇒ Recherche qui exige de la part de l'équipe de recherche une évolution des attitudes dans les relations avec les personnes concernées, une adaptation des méthodes, de la flexibilité et du temps

## PROJET



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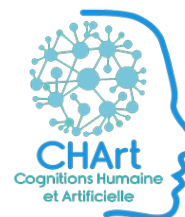


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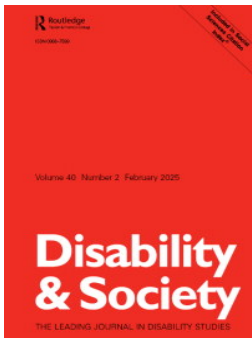
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# A participatory research to design a survey providing a portrait of the life of people with visual impairments

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## ABSTRACT

Little recent data is available about people with visual impairments in France. This article presents the design process of an online survey aimed at providing a portrait of the life of the people with visual impairments, based on participatory research. Questions were determined and refined over several phases, including focus groups and a consensus process using the Delphi method. A total of 49 people participated in the project: people with visual impairments, relatives, professionals and researchers. The participatory design process resulted in a final survey that includes 191 questions about various topics. The value and challenges of participatory research are discussed. For example, the participatory nature of the project and its reach encouraged participants to stay involved even though the development process was time consuming. The data collected with the survey will be used to capture the diversity of people with visual impairments in terms of (dis)ability, needs and resources.

## ARTICLE HISTORY

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## KEYWORDS

Low vision; blindness; Delphi method; focus group; daily life; community-based participatory research

## Points of Interest

- Little recent data is available concerning the daily life of people with visual impairment
- A survey was designed using participatory research with people with visual impairments, relatives or caregivers, visual impairment professionals and researchers.

- Focus groups and consensus methods were used to both give participants some voice to express their personal experience and select issues collectively judged as relevant.
- This paper illustrates that participatory research with people with visual impairments is possible, and presents the added value and main challenges of this approach.
- This survey will allow a better understanding of the French population affected by visual impairment and its impacts on a range of aspects of daily life.

## Introduction

Visual impairment can have significant impacts on various aspects of the daily life of those concerned and their relatives. Having a visual impairment is associated, for example, with decreased mobility (Douglas et al. 2011), reduced employment (Bell and Silverman 2018) and education access (Simui et al. 2018), as well as lower quality of life (Assi et al. 2021) and social participation (Desrosiers et al. 2009; Mick et al. 2018; Salminen and Karhula 2014). Visual impairment is also linked to an increased risk of health problems (Jones, Crews, and Danielson 2010) and mental health difficulties (Augestad 2017; Renaud and Bédard 2013). However, these impacts are heterogeneous and can depend on several factors, such as the severity of the visual impairment, its age of onset, personality traits, the presence of comorbidities, and the family. These difficulties can be lessened when the physical and social environments are accessible.

In France, little recent data is available concerning the daily life of people with disabilities (le Défenseur des droits [French independent public authority for rights], 2020; Special Rapporteur on the Rights of Persons with Disabilities 2019). The main source of information is the Handicap Incapacity Dependency survey conducted in 1999 to estimate the prevalence of health problems and their consequences on the daily and social life of people in France (Mormiche 1998). A statistical exploitation of that survey's data concerning people with visual impairments living in the community indicates a prevalence of blindness of 0.10% and of low vision of 1.94% (Brézin et al. 2005). The results indicated that visual impairment involves increased difficulty in carrying out daily activities, and a higher need for assistance and house adaptations. People with visual impairment in France also had fewer paid activities and lower incomes than those without (Brézin et al. 2005), and have difficulties in their daily travel (Sander et al. 2005). However, given that the survey was conducted over 20 years ago and was developed for all disabilities, it was not specific to visual impairment, and it may no longer accurately reflect the current situation.

Elsewhere, for example in Canada, a national study conducted on 198 working age adults with visual impairments revealed that access to information, transportation and formal and informal support are insufficient to meet needs (Gold and Simson 2005). In the United States, a study conducted on 7,210,535 people aged 45 or older indicated a prevalence of 2.8% of severe visual impairment and 1.6% of severe dual sensory impairment, and showed that these impairments are associated with cognitive and functional difficulties (Fuller et al. 2018).

In France, despite considerable financial and human resources, disability services often fail to meet the needs of people with disabilities. Hence, the focus is typically on disability management, instead of transforming society and the living environment to make these more inclusive (Special Rapporteur on the Rights of Persons with Disabilities 2019). Thus, the response to the needs of people with disabilities seems to be more based on the medical model of disability than on the social model, while the latter has considerably helped to change the image of disabled people and to identify and mitigate some of the social disabling barriers (Oliver 2013; Winance 2007).

The social model is rooted in the disability rights movement in the 1960s, when disabled people fought to make a distinction between disability and impairment, arguing that disability is more about the loss or limitation of opportunities that prevent people with impairments from participating socially like others because of physical and social barriers (Finkelstein and French 1993). In this vein, a criticism of traditional academic research on disability is that it focuses on impairments, and therefore contributes to the disability of the people concerned instead of improving their lives (Oliver 1992). In addition, traditional research is seen as alienating and disempowering by the disabled 'researched' (Kitchin 2000). Hence, the only way to improve life of disabled people with research would be to modify the social relations of research production, by involving them in the co-production of research (Oliver 1992). Being involved in the co-construction of research is a way to enable the disabled people to empower themselves, both through the transformation of the social relation of research (modification in power relations, reciprocity in benefits) and through the transformation of the material of research (Barnes 2003; Oliver 1992).

There is a variety of terms and forms of co-construction of research: democratic research, critical research, praxis research, emancipatory research, co-research, participatory research (Richardson 1997). Some of these forms encapsulate others, and they all share several values and principles; for example, dealing with research questions that matter to the concerned people, the use of methods that allow them for participation, and the construction of results aiming at better understanding of the nature of oppression experienced as disabled people and/or having a positive impact on their lives (Richardson 1997). Levels of participation of disabled people can vary,

according to how and by whom the research was initiated, the methods used, how disabled people can influence the research process and what happens to the results of the research (Zarb 1992). Although attractive, this ideal model of research, which differs from traditional academic research, can be complex to implement. Indeed, it involves the cooperation of actors from different backgrounds, so it requires from researcher the willingness to create innovative methodologies and to debate (Hodge 2008) and find more accessible formats for the dissemination of research findings (Garbutt 2009).

The Homère research project was launched on the initiative of eight major non-profit organizations in France and one public institution acting on behalf of people with visual impairments which need objective and recent data concerning the daily life, life trajectory, needs and resources of people with visual impairment in France. The ultimate aim is to better adapt their service offer and to claims from public policies a more effective and concrete consideration of needs. To fill this data gap, they drafted a call for proposals in which one of the conditions was that the research be co-conducted with people with visual impairments.

Based on an approach of community-based participatory research, i.e. with a research process that equitably involves organization representatives and researchers at all steps, a consortium was set up, composed of a community advisory board involving the non-profit organizations and the institution, and the research team (including a researcher who is also blind) that won the call for projects. The consortium was led by a member the community advisory board, who is a co-author of the present paper. Responding to a need identified by key actors in the field of visual impairment, the community advisory board then defined the project aim: to increase knowledge about people with visual impairments in France and their daily life, needs and resources, With the design of an online survey. In addition to being responsible for funding, the community advisory board supported the research team by bringing its expertise to determine the research questions, and provide input on research design. The community advisory board also participated in the survey diffusion, planning of data analysis, and the interpretation and dissemination of the findings. The community advisory board should also serve to increase the adoption and scope of knowledge resulting from the research, for example, in guiding public policy changes. Thus, the concerned people, represented by the community advisory board, are involved in all steps of the research. This present article is focused on how the survey was designed, using a participatory approach, and discuss the value and challenges of the participatory research process in this context.

## Research process

The survey design process involved four steps: the preliminary phase, the creative phase, the consensus phase and the final consultation phase.

### ***Recruitment of participants***

Participants of the creative phase and the consensus phase were recruited according to a purposeful sampling among the contacts of the consortium partners and by snowball effect. These two non-probability sampling methods are well suited when participants are hard to reach and when making inference about the population on the sample obtained is difficult (Etikan, Alkassim, and Abubakar 2016; Lysaght et al. 2016), as it is often the case with people with visual impairments. They were asked to participate in one or both of these phases, depending on their area of expertise, on their preference for participating as a group or individually and on their availability. All the participants of the creative phase were invited to contribute at the preliminary phase. The participants of the final consultation phase were representatives of the non-profit organizations on the community advisory board.

The recruitment criterion was to have an expertise in visual impairment, either as someone personally concerned or as a professional.

The project was conducted in compliance with the Declaration of Helsinki (World Medical Association 2013). Ethical considerations were discussed by the community advisory board, participants gave their oral consent and anonymity was guaranteed.

### ***Preliminary phase***

In the preliminary phase, participants were invited to answer an online questionnaire presenting a list of 82 subthemes divided into 15 main categories (e.g. health, school and education, employment, mobility, etc.). This list was based on themes and subthemes initially identified by the community advisory board and supplemented with the 77 life habits from daily activities to social roles described in the Assessment of Life Habits, a questionnaire developed to evaluate the social participation of people with disabilities (LIFE-H; Noreau et al. 2004). Participants were instructed to complete the list of subthemes as they deemed relevant. The completed subthemes list was then used to construct the semi-structured interview guides used in the focus groups of the creative phase.

### ***Creative phase***

The creative phase aimed to encourage participants to raise as many questions as possible on a large number of themes related to the daily life of people with visual impairments. Five focus groups with eight to nine participants each were carried out between 25 September and 16 October 2020, in person and by videoconference (due to the context of the COVID-19 pandemic). Three to four themes were addressed in each focus group: health, mental health and ageing, with 8 participants; schooling, early childhood, childhood, and

adolescence, with 8 participants; post-secondary education, work, housing and access to services and entitlements, with 9 participants; social life, sports, leisure and culture, emotional life, relationships, family and social environment and daily life activities, with 9 participants; and Information and digital accessibility, means of compensation and mobility, with 8 participants.

### ***Consensus phase***

The consensus phase aimed to select the questions considered the most relevant for the survey and ensure their understandability by reformulating them if needed. The Delphi method was used during this phase. This technique allows a group of experts to be questioned about areas of uncertainty in order to reach a convergence of opinions (Bourrée, Michel, and Salmi 2008; Ducos 1983; Williams and Webb 1994). This phase was iterative and involved two rounds, from 16 to 23 November and from 27 November to 3 December 2020. Using an online questionnaire processed on LimeSurvey, participants assigned a relevance score (/10) to each question and had the opportunity to propose rewordings of questions as well as response options. At the end of the questionnaire, participants could add other questions they considered relevant and were asked to give comments – for example, concerning the accessibility of the survey, since the final survey was planned to be presented in the same way. After the first round, questions with the highest convergence scores were selected, and those with the lowest scores were withdrawn. Questions for which opinions diverged were presented in the second round; of these, those with the highest convergence scores were selected. Word versions of the Delphi questionnaires were also produced on request for some participants.

### ***Final consultation phase***

In the final phase, questions and response options selected following the second consensus round were sent to the 6 representatives of the community advisory board and discussed during two phone meetings and several email exchanges between 16 and 23 December 2020. During this phase, final adjustments were made, deleting some questions and reformulating others.

Members of the final consultation phase were asked to focus on the wording of the questions (clear and concise sentences), their level of granularity (neither too detailed nor too broad), their ethical aspect (wording that is respectful of respondents), and the relevance of any conditional context (for example, some questions are contingent on the respondent's age). They were also asked to reflect on the survey as a whole: its fluidity, the overall logic, the links between the different sections, and its ease of completion. The



research team ensured that the content of the questionnaire defined in the previous steps was not modified during this phase.

### **Data analysis**

During the creative phase, the focus groups were digitally recorded and these recordings were then transcribed verbatim. The transcriptions were analysed *via* qualitative content analysis (Miles, Huberman, and Saldaña 2018) and reformulated in closed-ended questions and response options.

During the consensus phase, in the first round, a question was selected when the median relevance score was equal to or higher than 8/(10) and when at least 80% of participants rated it with a score of 8 or more. A question was rejected when the median relevance score was lower than 8 and when at least 30% of participants rated it with a score lower than 8. In the second (final) consensus round, a question was selected when the median relevance score was higher than 8 and when at least 80% of participants rated it with a score of 8 or more.

Throughout all phases, participants' oral and written remarks were collected to document the survey design process.

## **Results**

### **Participants**

In total, 49 people participated in the design of the survey: 23 in the preliminary phase, 41 in the creative phase, 36 in the consensus phase and 6 in the final consultation phase. Several participated in two or more phases: 3 participated in all four phases, 24 in the preliminary, creative and consensus phases, and 3 in the consensus and the final consultation phases. In the creative phase, participants choose participated at one or two focus groups according interests and expertise related to the addressed themes.

Participants were people with visual impairments ( $n=20$ ), relatives or caregivers ( $n=3$ ), visual impairment professionals (e.g. orientation and mobility specialists, social workers, psychologists;  $n=28$ ), and researchers ( $n=7$ ). Some professionals ( $n=5$ ) and some researchers ( $n=2$ ) were also visually impaired. The visually impaired participants had different profiles in terms of age, severity of visual impairment and employment, among other things. About one-third of the participants were involved in the non-profit organizations and the public institution of the community advisory board.

### **Survey design process**

Participants spent about 30min completing the preliminary phase questionnaire, 3 to 4h in focus groups during the creative phase and about 6.5h on average for each round of the consensus phase.

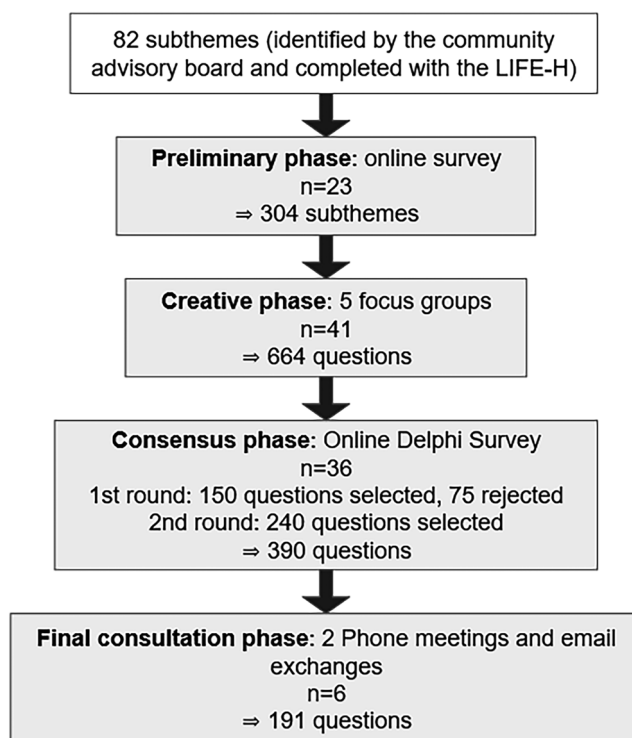
In the preliminary phase, 304 subthemes were obtained and these were integrated in the semi-structured interview guides used during the focus groups. A qualitative analysis of the content of the focus groups led to a first version of the survey, composed of 664 questions. As an example, here are some verbatims from the focus groups: *How long did it take to get a first diagnosis? How far away do you live from the clinic?* (vision screening subtheme), *Are you satisfied with your daily life? What activities do you do? What activities can you no longer do because of your age or disability? Do you have access to the activities you would like to do?* (social life, sports, leisure and culture theme), *Do you think that professors were sufficiently aware of your visual impairment and your study conditions?* (post-secondary education theme).

These 664 questions were assessed in the first consensus phase round and obtained a mean relevance score of 7.93 (SD = 2.24; median = 8, semi-interquartile interval = 1.5). Of these, 150 were selected during the first consensus phase and 73 were rejected. Based on participants' comments, some questions were added and others deleted due to redundancy, leading to a total of 407 questions to assess in the second consensus round. Overall, the accessibility of the survey used for the first round was perceived as good.

The participants' comments were taken into account for the second consensus round. For example, a document containing all the questions was attached to the second round online questionnaire to give participants a global view of the questions to be assessed. The 407 questions assessed in the second round obtained a mean relevance score of 8.37 (SD = 1.86; median = 9, semi-interquartile interval = 1). Of these, 240 were selected.

Of the 390 questions selected in the two consensus rounds, some were merged or deleted due to redundancy, leading to a total of 331 questions that were submitted to the members of the final consultation phase. The thematic distribution was modified for some of the questions: for example, all of the questions concerning ageing and adolescence were redistributed under other themes.

In the final consultation phase, the total number of questions was reduced to 191. To reach this number, some questions were merged and others were deleted due to redundancy, a modification of the level of granularity or for ethical reasons (e.g. some questions were judged too personal). Each decision was taken by majority vote. The survey design phases are summarized in [Figure 1](#). In the preliminary phase, 13-29 (mean = 19.0, SD = 5.1) subthemes per theme emerged, in the creative phase, 9-124 (mean = 41.5, SD = 28.6) questions per theme emerged, 5-53 (mean = 23.6, SD = 13.1) questions per themes were selected after the consensus phase, and 3-46 (mean = 14.1, SD = 10.6) question were validated after the final consultation phase. For example, concerning the health theme, 14 subthemes were found after the preliminary phase, 68 after the creative phase, 32 after the consensus phase, and 18 after the final consultation phase.



**Figure 1.** Survey design phases.

Overall, in each phase, questions were deleted, modified, added or kept as it is. Some questions were also merged together. Modifications could concern the formulation of the questions or of the answer options. For sensitive questions, in order to avoid forcing an answer, the options 'I don't know' or 'I don't wish to answer' were added during the last phase. For example, in the Common law procedures subtheme, one question (and answers) after the creative phase was: 'The reception in government services is sufficiently adapted: (Yes/Fairly well/Not very well/Not at all)'. During the consensus phase, this question was modified: 'The reception in the public services I use is sufficiently adapted for visually impaired people: (Yes/Fairly well/Not very well/Not at all)', and, after the final consultation phase, the possible answers were modified: 'The reception in the public services I use is sufficiently adapted for visually impaired people: (Yes/Fairly well/Not very well/Not at all/I don't know)'.

Thus, the final core survey arising from the design process consists of 191 questions. Among them, 40 are targeted to parents of visually impaired children under the age of 16. The other 151 questions are targeted to people with visual impairments aged 16 or over, 59 of these are aimed at all respondents, and 92 depending on the respondent's profile. For a given respondent, the total number of questions asked will depend on his/her profile. For

example, if the respondent's visual impairment appeared in adulthood, questions about schooling will not be asked.

In addition to the core survey, 44 questions about socio-demographic and visual impairment characteristics and functional abilities were added. These were not selected through the participatory method presented here.

## Discussion

The Homère project was constructed with a participatory research approach to design a data collection survey with and for the people concerned. The survey design involved 49 participants with different profiles. Some were visually impaired or their relatives, others were visual impairment professionals or researchers. This heterogeneous participation allowed several perspectives with differences and similarities. The visually impaired participant profiles were also diverse in terms of age, severity of visual impairment, employment, or involvement in different organizations.

The preliminary phase was based on themes initially identified by the community advisory board and the items of the LIFE-H with the objective to have a list as exhaustive as possible of the areas of daily and social life in which participants might encounter barriers. The LIFE-H is conceptually constructed on the Disability Creation Process (DCP; Fougeyrollas et al. 1988), a social model of disability which shares similarities with the International Classification of Functioning, Disability and Health (ICF; World Health Organization 2001) such as a systematic and universal approach, the objective to describe the complex and dynamic process of human functioning and the consideration of personal and environmental factors in the performance of activities in life situations (Levasseur, Desrosiers, and Tribble 2007). The LIFE-H is meaningful to evaluate the participation in daily life activities and social role domains (Noreau et al. 2004).

Several strategies were used in order to adapt the research process to the participants as much as necessary. For example, some of the design phases were conducted in groups, others were individual, and the participants chose the phases they wished to participate in according to their preference and availability. In addition, although efforts were made to make the online questionnaires of the Consensus Phase as accessible as possible, some blind participants were allowed to answer directly on a word form, if they felt it was more comfortable for them. Moreover, solutions were implemented to limit the effect of fatigue at different phases of the process: during the Creative Phase, breaks were offered to participants; for each round of the Consensus Phase, respondents could complete the questionnaire in several times.

One of the main challenges in the survey design was to find a trade-off between addressing all the themes of interest and a length that would not

be too time-consuming to complete for respondents. As the non-profit organizations and the public institution involved in the project were diverse in terms of the population of interest (young people, adults, aged people), the services provided, and the available resources, all aspects of daily life addressed by the survey were considered relevant by the community advisory board. As indicated by the high relevance scores obtained at the two rounds of the consensus phase (median equal to 8 and 9, respectively), it was difficult to reduce the length of the survey.

Another challenge was the time constraints for the survey design, due to funding. Time constraints reduced the possibility of carrying out several focus groups per theme in the creative phase, or additional rounds in the consensus phase. Nonetheless, in the consensus phase, while participants had the possibility to add new questions, no major subthemes arose, suggesting that data saturation was reached during the focus groups. A third round of Dephi during the Consensus Phase would have been optimal to fine-tune the survey. Instead, and as suggested by the community advisory board, final adjustments to the survey were made with six representatives of the community advisory board (Final Consultation Phase). In addition to reduce the time spent, this option had the advantage to limit the burden on the participants. The main drawback of this option was the risk that the survey would be modified according to the personal opinions of the Final Consultation Phase participants. To limit this, the aim of this phase (i.e. optimizing the completion of the questionnaire and ensuring that the questions were ethical) was reminded by the research team when necessary. For example, one participant of the Final Consultation Phase wanted to remove the questions about sexuality. Since these questions had been selected during the Consensus Phase, they were kept, but the following mention was added beforehand: *Here is a series of questions about emotional and sexual life, which is a component of health and well-being according to the World Health Organization. For each of them, you can select the answer 'I do not wish to answer'.*

Furthermore, the completeness of the survey is reinforced by the fact that the final version addresses all the main topics found in studies aiming to identify the research priorities of people with visual impairments in the Netherlands (Schölvinck, Pittens, and Broerse 2017) and in Scotland (Duckett and Pratt 2001), and, more broadly, almost all of the research priorities identified for disability research in Europe (Priestley, Waddington, and Bessozi 2010).

The resulting survey demonstrates that the participatory process is relevant and feasible for such an objective, even when partially performed remotely due to the COVID-19 pandemic. The design process was time consuming for the participants, but they expressed willingness to maintain their participation because they felt involved due to the participatory approach, the addressed issues, and the reach of the survey. The participatory nature of

the Homère project were made possible thanks to a shift of language, roles and attitudes in the social relations of research, the adaptation of research methods and the flexibility and the time taken enabling the participation of the concerned people (Rix et al. 2020).

The method presented in this paper seems to be particularly relevant in the context of research in co-construction with disabled people. Indeed, the Creative Phase allowed the concerned people to highlight their subjectivity by giving them some voice to express their personal trajectory. On the other hand, the Consensus Phase enabled the selection of relevant issues from a collective perspective.

To date, few studies aiming to better understand the views and experiences of people with visual impairments have been conducted using participatory methods; among participatory research studies published in English, Spanish or German, a literature review found that only two involved visually impaired participants (Rix et al. 2020). However, participatory research has been used successfully with children and adults with visual impairments in the context of object and technology design – for example, tactile books for children or technological mobility aids (Brock et al. 2010; Frauenberger, Good, and Keay-Bright 2011; Valente, Bara, and Gentaz 2018; Valente et al. 2022).

After the design of the survey, the next challenge in the Homère project was its deployment. Given the target population, efforts have been made to ensure it can be completed by as many respondents as possible. The wording of the questions and response options were worked on during the design process to be as clear and unambiguous as possible. A priority was placed on the accessibility and user-friendliness of the questionnaire, which was achieved in part through the integration of participant feedback in the Consensus Phase. Its main mode of delivery was online, which can present obstacles for the visually impaired: respondents had the possibility of submitting their answers online (in several stages if necessary) with the support of a caregiver or by telephone. In order to reach as many people with visual impairments as possible, including those hidden from visual impairment services, the survey has been promoted by non-profit organizations, the media, social networks, and region-by-region launch events with local organizations, public institutions and political representatives. These efforts have been collectively supported by the community advisory board and the research team. In addition, civic service volunteers administered the survey in face-to-face interviews to attempt to reach people with visual impairments less likely to respond to online surveys. Deployment began in February 2021 and finished in June 2022. By the end of the data gathering, 2,364 respondents had answered the entire survey (11% by telephone), indicating the relevance of the means of diffusion. The ongoing subsequent phases of the project, i.e. the data analysis and the dissemination of the findings, are implemented

with the implication of the community advisory board, with the objective that research will have benefits for people with visual impairments.

Beyond the survey and the usefulness of the results that will come out of it, the Homère project and its participative approach has allowed the synergy of various key actors in the field of visual impairment to be brought together around a common work. The actors of the Homère project, whether they are non-profit organizations members or researchers, have thus see the interest and the added value of continuing to work together, and they have the intention to develop an Observatory of the visual impairment.

## Conclusion and implications

To our knowledge, the Homère survey is the first in France to investigate a range of aspects of life of people of all ages with a visual impairment. It was designed using a participatory method alternating group and individual phases. This participatory approach illustrates how the people with visual impairments, through non-profit organizations and a public institution acting on their behalf, can be stakeholders in research affecting them. This kind of research is feasible, but requires from the research team shift in attitudes in the relations with people concerned, adaptation of methods, flexibility and time. The ultimate objective of the Homère survey is to capture the diversity of the visually impaired across France in terms of demography, (dis)ability, needs and resources. The results will highlight the needs of people with visual impairments in terms of equipment, services or infrastructure, allowing the organizations and institutions involved to influence policy through lobbying. The active involvement of people with visual impairments as stakeholders in the initiation of the project, the development of the survey and in the adoption and dissemination of its findings might help to lead to their emancipation from a disabling society (Duckett and Pratt 2007).

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No potential conflict of interest was reported by the authors.

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