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Becoming a coresearcher in dementia care research: a mixed-methods study protocol for evaluation of the *Dementia Leaders* programme

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ABSTRACT

Introduction The *Dementia Leaders* programme aims to enhance active public involvement in dementia research by developing a programme for potential coresearchers that includes the perspectives of individuals who experience the disease directly, such as people living with dementia, their informal caregivers and healthcare professionals. The planned study will evaluate this programme (which includes workshops, webinars and online meetings) with a focus on, for example, the content and structure of the programme as well as the experience of the participants regarding their active involvement.

Methods and analysis A mixed-methods design will be used to evaluate the Dementia Leaders programme. For this purpose, we will conduct semistructured interviews with the participants in the programme. Additionally, we will conduct an online survey after each webinar associated with the programme. The data will be analysed using qualitative content analysis (for the interview data and the open-ended questions included in the online survey) and by employing descriptive statistical methods (for the closed-ended questions of the online survey). Finally, the results obtained via both analytical methods will be synthesised, interpreted and discussed.

Ethics and dissemination This study received approval from the ethics committee of the German Society of Nursing Science (Number 25-014). The results will be presented and published alongside the coresearchers at (inter)national conferences and in journals targeting practitioners, caregivers and people living with dementia as well as in peer-reviewed journals.

INTRODUCTION

The active involvement of the public in healthcare research is crucial to ensure that research addresses the needs of the people. Such public involvement (PI) highlights the principle that the individuals who are affected by a given phenomenon have the right to shape publicly funded research on that topic.[1] The integration of lived experiences through active PI can lead to healthcare solutions that are better suited to real-life needs, thus increasing the chances of successful implementation.[2]

STRENGTHS AND LIMITATIONS OF THIS STUDY

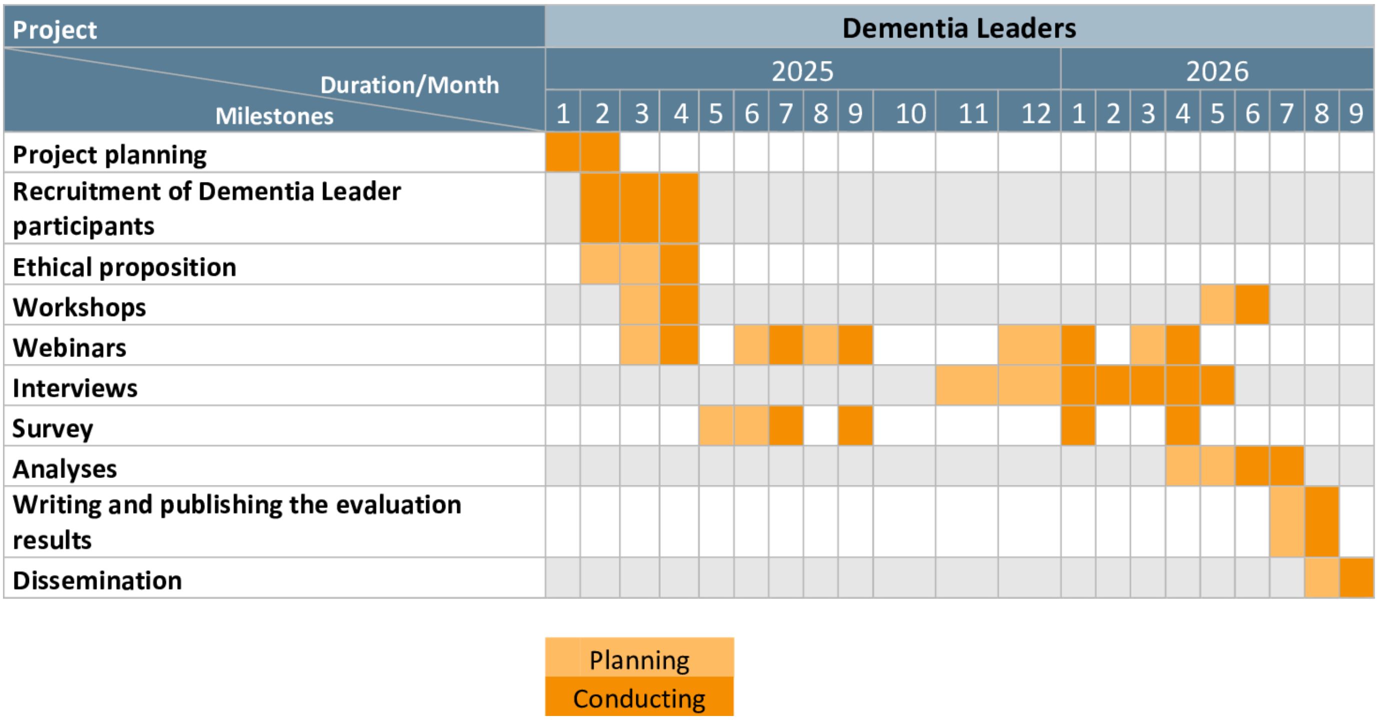
- ⇒ The mixed-methods process evaluation allows us to gain insights into how the programme works while the programme is ongoing, thereby enabling us to adapt and learn throughout the programme.
- ⇒ People with dementia, informal caregivers and healthcare professionals will be included in the evaluation, thus offering a more holistic perspective and allowing under-represented groups to be included in the research as both research participants and coresearchers.
- ⇒ The use of the DECIDE-SR model ensures that individuals' degree of involvement in different phases of the project is tailored to their individual needs and preferences.
- ⇒ As a result of the relatively small sample size in the planned evaluation, the task of ensuring a diverse sample may be difficult.

Academic research often remains disconnected from practical applications.[3] Especially in the context of dementia research, a gap in active PI persists, especially given that most research on this topic has focused mainly on people without cognitive impairment.[4–6] For many years, people living with dementia have been excluded from research with the aim of protecting them as a vulnerable group; however, many people living with dementia have objected to this approach and emphasised the importance of ensuring that their perspectives are heard in line with the slogan 'nothing about us without us', which originates from organisations for people with disabilities.

Since the 1980s, interest in PI in research has been increasing with the aim of improving efforts to establish connections between researchers and care users, carers, families and communities.[7–9] This approach supports the establishment of partnerships with people who have lived experience with health conditions, thus enabling them to contribute to the research on the basis of their knowledge and expertise.[9] Accordingly, the term ‘coresearchers’ has been developed to describe such participants, who are fully integrated into the research team as equal peers, rather than only serving the role of informants.[10] Coresearchers who are involved in consultation pertaining to research activities, such as by advising researchers and participating in the analysis of data, represent one example of such efforts to promote the active involvement of members of the public. The extant research involving people living with dementia has focused on, for example, the development, evaluation and implementation of healthcare interventions through consultation with individuals who have experienced dementia.[11] However, the tasks of fostering sustainable collaborations among researchers, people living with dementia, caregivers and healthcare professionals and enhancing shared learning while simultaneously developing a model for such involvement are also essential.[12]

The Dementia Leaders programme aims to strengthen active PI in dementia research by developing a programme to foster potential coresearchers with the aim of incorporating the perspectives of the individuals who experience this disease directly. By creating opportunities for active participation, the Dementia Leaders programme seeks to empower people living with dementia, caregivers and healthcare professionals and to enable them to participate actively in research. It promotes an inclusive approach to dementia research that takes into account the diverse and often unheard experiences and knowledge of these individuals. The name ‘Dementia Leader’ was suggested by a person with dementia with whom we have collaborated closely for many years. The term coins how people with lived experience of dementia can be leaders in the field, showing researchers, politicians and organisations the way forward. Through and with the Dementia Leaders programme, we want to empower people to take on this role. The Dementia Leaders programme is run by the German Center for Neurodegenerative Diseases (DZNE), site Witten, Germany. The programme is local, but if the evaluation shows promise, we hope to scale it, first to other German research centres and later potentially internationally. The programme consists of two in-person workshops in Witten at the beginning and end of the programme as well as webinars (see figure 1 for an overview of activities in the Dementia Leaders programme). All workshops and webinars will be co-organised by members of the research team and participants in the programme (see figure 1). The content of the different webinars and the two workshops will be codeveloped with participants in smaller groups, based on their interest. These smaller groups will plan, prepare and conduct the webinars and workshops.

The Dementia Leaders programme builds on the experiences and participation framework that have been developed in previous projects (DECIDE-SR and PreBeDem),[6 12] which have been implemented at the DZNE Witten. The main goal of the framework is to describe how people living with dementia, those in their social networks and healthcare professionals can be actively engaged and involved as coresearchers in dementia care studies. A framework for active involvement in systematic reviews was developed on the basis



Project	Dementia Leaders																				
Duration/Month Milestones	2025												2026								
	1	2	3	4	5	6	7	8	9	10	11	12	1	2	3	4	5	6	7	8	9
Project planning	■	■																			
Recruitment of Dementia Leader participants		■	■	■																	
Ethical proposition		▨	▨	■																	
Workshops			▨	■													▨	■			
Webinars			▨	■		▨	■	▨	■			▨	■		▨	■					
Interviews											▨	▨	■	■	■	■	■				
Survey					▨	▨	■		■				■			■					
Analyses																▨	▨	■	■		
Writing and publishing the evaluation results																			▨	■	
Dissemination																				▨	■

▨ Planning
■ Conducting

Figure 1 Timetable: a timetable of the activities in the Dementia Leaders programme and the process evaluation.

of a previously developed model,[13] thus allowing coresearchers to select their preferred degree of involvement during the different stages of the review (eg, the development of the research question, screening process and analysis). The model aims to facilitate involvement in different phases of research, including methodology, data collection, analysis and dissemination. This project highlighted valuable lessons pertaining to cobuilding, impact, support, mutual respect and inclusivity in the context of dementia research. Coresearchers significantly influenced the focus of this research on the basis of their lived experiences.[12] The evaluation of the Dementia Leaders programme is the first critical reflection of the application of the previously developed framework.

The Dementia Leaders programme similarly focuses not only on empowering individuals but also on working with the model for involvement in dementia research, including by testing its applicability beyond the specific task of conducting systematic reviews. Throughout the programme, we will promote active engagement and involvement in the development of the programme, including the development, planning, organisation and conduction of and participation in webinars and workshops. As the Dementia Leaders programme itself is participatory, we did not yet decide which overarching topic we should address. We only defined dates for workshops, meetings and webinars. This allows the participants to define the content, to decide how to present their thoughts, experiences and findings in the webinars and to be a part of the research (eg, conduct brief interviews with people from their social network). This type of participatory collaboration is key to the Dementia Leaders programme. The programme encourages long-term engagement by establishing an environment that is conducive to the exchange of experiences between coresearchers and professional researchers, in which context all involved parties engage in cotraining and colearning. Understanding how coresearchers (eg, people living with dementia, informal caregivers and healthcare professionals) experience the workshops, training and research activities can support refinements and improvements to the programme over time. By assessing aspects such as content, structure, involvement and overall organisation, the programme aims to ensure that everyone receives meaningful exchange and accessible support. Therefore, the planned study aims to evaluate the Dementia Leaders programme.

METHODS AND ANALYSIS

This evaluation aims to investigate the experience of the various coresearchers (eg, people living with dementia, caregivers and healthcare professionals) who have been involved in the workshops, webinars and meetings associated with the Dementia Leaders programme as both developers and participants. By collecting feedback regarding the content and structure of the meetings as well as the involvement of the participants, we aim to improve the participatory approach and the Dementia Leaders programme overall. This aim leads us to ask the following questions:

1. What do participants expect from the Dementia Leaders programme, and are these expectations fulfilled?
2. How do participants experience the participatory development of the Dementia Leaders programme?
3. How do participants experience the Dementia Leaders programme?

To evaluate the Dementia Leaders programme, we will implement a mixed-methods approach using a convergent design that involves both interviews with the participants in the programme and an online survey. The Dementia Leaders programme will run from April 2025 until June 2026, and the evaluation is scheduled from August 2025 until August 2026. Figure 1 illustrates the timetable of the Dementia Leaders programme. A completed checklist on Standards for Reporting Qualitative Research can be found in the supplementary materials.

Recruitment and access

To recruit participants to evaluate the programme, a convenience sampling approach[14] will be used for the interviews, which will focus on individuals who have lived experiences of dementia, informal caregivers and healthcare professionals involved in the Dementia Leaders programme. We will apply the same inclusion criteria we use for the inclusion in the Dementia Leaders programme: people with a dementia diagnosis, informal caregivers or healthcare professionals. Participants in the process evaluation must participate in at least two activities of the Dementia Leaders programme. We will monitor the participation of each session. We decided not to conduct a clinical dementia test since the participants with a dementia diagnosis are becoming coresearchers. This allows us to be as inclusive as possible and let the people with dementia themselves choose whether they want to be included as coresearchers and as participants in the process evaluation. We will describe and report demographic characteristics such as gender, age, ethnicity and type of dementia in our results paper. However, the final sample will be shaped by voluntary participation. For the online survey, a self-selection sampling approach will be used; specifically, all the webinar participants will be invited to complete this survey, and those who are interested may respond anonymously.

People with dementia and informal caregivers who participate in the Dementia Leaders programme receive reimbursement for the time they spend on the programme as well as the time they spend in interviews. Participants of the online survey will not receive incentives.

Recruitment for the interviews

We expect to include approximately 25–30 participants in the Dementia Leaders programme. We aim to recruit approximately half of the participants for the interviews. The online survey will be sent out to every participant of the webinar directly after the session is completed. The sample will include individuals living with dementia, informal caregivers of people living with dementia and health professionals. At the beginning of the programme, we will inform all participants of the opportunity to participate in an interview, and this information will be repeated in emails and during events. To participate in the process evaluation, status as a coresearcher in the Dementia Leaders programme is required. Inclusion is based on individuals' willingness and ability to participate in the process evaluation. Individuals with dementia, caregivers and healthcare professionals who express interest are welcome to participate in this project. If an uneven distribution of the groups becomes evident in the participant groups, we will document this point and take it into account in our interpretation of the evaluation data. No group will be excluded on the basis of numbers, as the aim of this investigation is to capture the experiences of all interested and engaged individuals. When people express interest in participating in the interviews, we will schedule dates for the interviews in line with their preferences, including their preferences regarding whether the interviews should be conducted online or face-to-face. To give potential participants an initial impression of the researcher conducting the interviews, the researcher will introduce themselves and the interview process at one of the accompanying Dementia Leaders social events and will be available to answer questions.

Recruitment for the online survey

At the beginning of the Dementia Leaders programme, we will inform all participants in the programme of the opportunity to complete the anonymous survey after each webinar. At the end of each webinar, we will encourage all the participants to complete the anonymous survey. A link to the anonymous online survey will be sent via email to all participants immediately after the webinars.

Interviews

We plan to conduct a total of 12 interviews with people who help develop and participate in the Dementia Leaders programme. The interviewees will include people living with dementia, informal caregivers of people living with dementia and healthcare professionals. We plan for each interview to last 30–45 min, and the interviews will be conducted either online or in person depending on the preferences of the participants. These interviews will be semistructured on the basis of our interview guidelines, thus ensuring that we can obtain insights into a predefined set of topics. The interview guidelines can be found in the supplementary material. However, participants will also be allowed to direct the conversation towards the points that are most relevant to them, thus allowing us to expand our insights beyond the predefined areas. The research team developed the interview guidelines in accordance with the description provided by Kallio *et al*.[15] We prepared the interview guidelines and predefined set of topics for several group discussions based on the combined experiences of the research team in conducting evaluations, researching and working with people with dementia, informal caregivers and health professionals. The interview guidelines are semistructured and can therefore be adapted to the needs and interest of the person participating in the interviews. To ensure that the interviewees can speak freely, a researcher who has experience in qualitative research, particularly with respect to interviews conducted with people living with dementia, informal caregivers and healthcare professionals, will conduct the interviews; this researcher will not participate in the webinars.

Survey

We plan to conduct an anonymous online survey after each of the four webinars. This survey will focus on evaluating each webinar, particularly in terms of the content, moderation and organisation. An overview of our survey questions is provided in the supplementary material. The online survey will be conducted using the online survey tool Lime Survey, and the survey will take 10–15 min to complete. We will pilot the survey with one person with dementia and include their feedback in the final survey. We decided to make the survey anonymous to give the participants a space where they can share freely knowing that they will not be recognised. We chose to combine the interviews with a survey as this enables us to evaluate every single webinar and adapt the following webinars to the needs of the participants. This real-time evaluation is more flexible than the interview format, which involves recruiting participants and finding a time suitable for everyone involved. Instead, the interviews provide more in-depth information and reflections on the programme as a whole.

Data analysis

The data collected via the interviews and surveys will be analysed based on a mixed-methods approach using a convergent design, which enables us to collect data from the survey as well as the interviews while the Dementia Leaders programme is ongoing. Closed-ended survey responses will be evaluated using descriptive statistical methods (eg, mean, SD and frequency) with the assistance of Microsoft Excel software; the goal of this evaluation will be to identify general patterns and trends. The open-ended survey responses and interview transcripts, which will be produced by a professional, external transcription office, will be analysed by conducting a qualitative content analysis,[16] in which both inductive and deductive coding will be used to identify key themes pertaining to participants' expectations and experiences. Since the aim of the survey is to learn how the participants perceived the content and presentation of the content during the webinar, we assume that in case of missing data, the participants did not want to/could not comment on this factor. Accordingly, we will also include incomplete data sets in the analysis. A person who did not participate in the online survey could still provide their impressions during the interviews.

All the data will be coded with the assistance of the qualitative data analysis software MAXQDA[17] V.26.0 by two researchers together (MRM and ALH both are experienced (post/predoc) qualitative/mixed-methods researchers) and subsequently interpreted, reflected on and discussed by the research team, including coresearchers from the programme (people with dementia, informal caregivers and health professionals). The research team behind Dementia Leaders is a diverse team with different backgrounds, nationalities and genders. Before analysis starts, the two researchers performing the analysis will meet to discuss potential bias and prejudice to be aware of this during the analysis. They will also discuss the analysis with the rest of the research team and the Dementia Leaders participants to ensure that different perspectives are being heard and to minimise bias. After the analysis of the last two interviews, the abovementioned researchers will check whether they note any new codes; if no new codes are identified, we will assume that we have reached data saturation.

This combined approach will enable us to obtain a comprehensive understanding of the Dementia Leaders programme from multiple perspectives.

Patient and PI statement

People with dementia and their informal caregivers will be involved at all stages of the research. Healthcare staff will also be involved throughout the project; however, they were not involved until the Dementia Leaders programme started, whereas people with dementia and informal caregivers were also involved in the processes of generating ideas and writing the funding proposal for the Deutsche Demenzhilfe. Further details concerning patient and PI are provided throughout the protocol.

Ethics and dissemination

The research follows the guidelines stipulated by the Declaration of Helsinki,[18] and the data collected as part of this research will be treated in accordance with the EU Data Protection Regulation.[19] Throughout the research, we will use respectful terminology and avoid stigmatising language, as recommended by several organisations that work with people living with dementia.[20]

We will obtain written informed consent from all the participants in the interviews. Capacity to consent will be assessed by implementing the two-step approach described by Smith *et al*,[21] which will involve an initial expression of interest prior to participation in the Dementia Leaders programme followed by a final capacity judgement, which will be made by the responsible researchers before the interviews are conducted. Only individuals who understand the information and who sign the informed consent form will be included in the process evaluation. On the basis of previous research and experience, we know that many people living with dementia, particularly in the early to moderate stages of the disease, can make autonomous decisions, express their views and provide informed consent. This approach is in line with the German AWMF guidelines regarding consent for people living with dementia in the context of medical measures.[22]

The results of the evaluation will be presented alongside the coresearchers at (inter)national conferences and published in journals targeting practitioners, caregivers and people living with dementia as well as in peer-reviewed journals.

Limitations

The Dementia Leaders study has some limitations. In particular, the Dementia Leaders programme consists of a small group of participants. Therefore, the evaluation of the programme will only provide a first descriptive impression of how the programme has been perceived by the participants. More research is necessary to evaluate the Dementia Leaders programme on a broader scale and to refine the programme based on the experience of participants.

A further limitation lies in the inclusion criteria of people living with dementia, in which we decided to let people with dementia choose themselves whether they wanted to participate. Further research could ask people living with dementia based on a clinical dementia rating. However, based on research about capacity consent in the medical treatment of people with dementia, a negative cognition test is not equal to not being able to be a coresearcher or to provide consent.[22]

A clear definition of every step regarding the programme's content is not possible at this stage since we will develop the programme together with the participants. We believe that the participatory approach is a strength of this study; however, the participatory approach challenges the reproducibility of the study and the programme.

Currently, we have initiated preparations for a follow-up study that will allow us to address the current limitations of our evaluation.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Provenance and peer review Not commissioned; externally peer-reviewed.

Data availability statement .

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