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Identifying future research priorities for diversity-sensitive psychosocial interventions to manage dementia-related symptoms (GenderDem): protocol for a priority setting partnership study

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ABSTRACT

Introduction Gender, sex and ethnicity-sensitive approaches to psychosocial interventions for behavioural and psychological symptoms of dementia have been under-represented in the literature. Although the initial findings have revealed relevant differences with regard to sex, gender and ethnicity-sensitive approaches to those interventions. The GenderDem study aims to identify the top-10 research priorities in this context for future dementia care research.

Methods and analysis The methodological approach in GenderDem is based on the James Lind Alliance Guidebook and the concept of priority setting partnerships. In this participatory research approach, people living with dementia, their caregivers (and/or their loved ones) and healthcare professionals will be actively involved in the study. As members of a steering group, they act as coresearchers in the GenderDem study. We aim to recruit a diverse group of people for the steering group by considering different factors, eg, gender identity, sex, ethnicity and age. Future research priorities will be identified through two rounds of online surveys to collect and rank research topics from additional participants (eg, people with dementia, caregivers and/or loved ones and healthcare professionals). Additionally, a literature review and a workshop will be carried out in parallel to consider the current state of the research and to finalise the top-10 research priorities.

Ethics and dissemination An ethics application for conducting the two surveys and the workshop for this study has been approved by the German Society of Nursing Science (No. 25-029). Study participants will be informed in detail about the voluntary nature of their participation. Together with the coresearchers from the steering group, we will develop a dissemination plan that considers the different media consumption forms of the various groups. Additionally, we will disseminate our project results on an ongoing basis.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ People from different groups (people living with dementia, caregivers and/or loved ones and healthcare professionals) will be actively involved as coresearchers in all stages of the partnership setting priority study.
⇒ We assume—on the basis of the expertise contributed by the coresearchers—that the online surveys and workshop can be tailored to the participants.
⇒ We assume that it is difficult to access groups of people in this research setting, and that such groups include those who have little connection to healthcare or dementia support services and people experiencing inequity or inequality.

INTRODUCTION

By 2033, the number of people living with dementia (PLWD) in Germany is expected to increase to between 1.65 and 2 million.[1 2] The increasing number of dementia cases is a challenge worldwide regarding organising and financing dementia-related care and support.[1 3] In particular, behavioural and psychological symptoms of dementia (BPSD)—such as emotional disturbances (eg, depression, anxiety, apathy), psychotic symptoms (eg, hallucinations) or behavioural changes (eg, repetitive movements)—pose challenges for non-professional caregivers and/or loved ones as well as for healthcare professionals.[4 5] BPSD is estimated to affect up to 90% of all people with dementia in the course of their dementia disease.[6] In Germany, this rate means that approximately 1.5–1.8 million people with dementia will experience these symptoms over the

trajectory of their life after receiving a dementia diagnosis.[1 6] Women appear to be at a higher risk of developing dementia because of various factors, such as a longer life expectancy or comorbidity with other diagnoses such that women have a higher lifelong prevalence (eg, depression).[7] In addition, different groups of people, such as members of the LGBTQIA+ community, despite their greater vulnerability to dementia differ notably in their access to adequate diagnostic processes.[8 9]

Although relatively little scientific knowledge is available concerning gender, sex and ethnic differences in BPSD, such differences appear to exist.[10] A definition of the concepts sex, gender and ethnicity as well as the interaction of the concepts in the sense of intersectionality can be seen in a glossar in the online supplemental material (No.1). For example, studies have shown that women with dementia are more frequently described as experiencing paranoia, delusional ideas, hallucinations, affective disorders, anxiety disorders and phobias. However, the behaviours of men are more often described in terms of hostility and diurnal rhythm disturbances.[11] Women with dementia are therefore at high risk of inadequate treatment for dementia-related symptoms because of a lack of sex-sensitive and gender-sensitive healthcare.[7]

In terms of ethnicity, nonwhite or ethnically diverse people are underdiagnosed with BPSD,[12] which may lead to insufficient provision for therapies and services as well as poor outcomes. Additionally, ethnic minority groups are underrepresented in clinical trials and therefore receive nontailored interventions.[13 14] This situation also applies to family caregivers from ethnic minority groups, who report a higher perceived stress level than other family caregivers because of greater barriers to accessing support services and because existing services do not meet their needs.[15]

Furthermore, BPSD is correlated with the degree of cognitive and functional impairment and thus with the degree of care needed by the person with dementia.[3 6] Moreover, BPSD is associated with distress among nonprofessional caregivers and healthcare professionals, avoidable hospitalisation, the inappropriate use of medications and high health and care costs.[6] Meanwhile, the underdiagnosis of BPSD in nonwhite people must be considered, as it further affects access to adequate care and treatment for symptoms that are easily treatable with medication.[12]

Psychosocial interventions seem to be gender stereotyped and oriented towards a Western understanding of person-centred care.[5 16–18] Nevertheless, these interventions are considered ideal treatments for BPSD symptoms.[8 16–18] Regardless, some uncertainties remain regarding these interventions in terms of their diversity sensitivity or efficacy for different groups of people.[10 19] For example, the current guideline for the treatment of dementia in Germany addresses psychosocial interventions as a treatment for BPSD briefly without elaborating on a diversity-sensitive context.[16] A current study reviewed psychosocial intervention recommendations in guidelines with a focus on social health and intersectionality. The results confirm a lack of diversity-sensitivity in psychosocial interventions as well.[20]

A recently published study revealed a link between ethnicity and the diagnosis process of dementia-related symptoms (such as BPSD) in clinical care settings.[12] Another recently published study revealed how culture, ethnicity, dementia and stigma intersect and influence the lives of people with dementia.[21] Tailoring psychosocial interventions to aspects of sex, gender and ethnicity seems to be a topic ignored in dementia research, although different diversity factors appear to affect the efficacy of these interventions.[10 19 22 23] This finding supports the relevance of addressing this research gap and the need to consider the diverse characteristics of PLWD to develop or provide tailored psychosocial interventions.

To address this research gap, the GenderDem study—which began in July 2025 and is expected to end in December 2026—will use the method and principles of the James Lind Alliance (JLA) for priority setting partnerships (PSP) for an active participatory collaboration with people with dementia, their caregivers and/or loved ones, and healthcare professionals as coresearchers.[24] By conducting our research together with various groups of people as coresearchers, we are creating a space for collaborative research, which provides the opportunity to incorporate the experiences and perspectives of each member actively into the identification and prioritisation of research topics for dementia care research. This method enables us to construct intersectional perspectives not as outsiders only, which would risk misrecognising perspectives and thus perpetuating epistemic violence in the scientific context.[25 26]

AIM

The aim of our GenderDem study is to identify future research priorities for gender, sex and ethnicity-sensitive dementia research, with a focus on managing BPSD.

Accordingly, the study intends to answer the following research question:

1. What are the top-10 future research priorities for gender, sex and ethnicity-sensitive psychosocial interventions to manage BPSD in people with dementia?

METHODS

The GenderDem study runs from July 2025 to December 2026.

Patient and public involvement within the PSP

The JLA provides a guidebook that explains the concept and methodical approach to establishing a PSP.[24] The PSP will be used as the methodological approach in GenderDem. The PSP approach requires the involvement of a variety of stakeholders, in our case people with dementia, their caregivers (and/or loved ones) and healthcare professionals who will act as coresearchers in the entire research process. Specifically, PSPs include the

creation of a steering group, which in our study consists of those stakeholders. The role distribution and involvement degree within the steering group and by the coresearchers are agreed on jointly.

To determine the degree of involvement in a manner appropriate to our target group, we will follow the description of the Guidebook but make an adjustment. We will apply the DECIDE-SR framework[27 28] to structure the participatory involvement of people with dementia, their caregivers (and/or loved ones) and healthcare professionals in our study. This framework offers five levels of involvement in the research process, ranging from receiving information to leading processes as shown in figure 1. The degree of participation in the individual work steps (eg, conducting the survey or screening articles in the review) is determined individually by the coresearchers.

While the PSP-method is flexible in use, the key principles will remain the same, although we will integrate the DECIDE-SR approach to ensure that the different members of the steering group are equally involved. The use of the DECIDE-SR approach allows us to involve the members of the steering group equally and in an accessible manner. The structured approach explicitly developed for participative research with PLWD enables each member of the steering group to decide on the degree of involvement in each step of the study based on their interests, capabilities and availabilities.

Methodological framework of the PSP

PSPs are intended to identify the top-10 priorities for future research in a specific field.[24] Therefore, the aim of the above-mentioned research question is to work together with coresearchers to identify research interests from participants representing different groups of people (eg, people with dementia, caregivers and healthcare professionals) regarding sex, gender and ethnicity-sensitive psychosocial interventions to manage BPSD and to reduce these to identify the top-10 future research priorities.

To achieve this goal, the PSP entails a six-step detailed research process, including the recruitment of the steering group (PSP step 1), two online surveys (PSP steps 2a and 4), a review (PSP step 2b) and the synthesis of the results (PSP step 3), a participatory workshop (PSP step 5) and the dissemination of the results (PSP step 6).

The adapted PSP methodology process is shown in figure 2.

PSP step 1: recruiting coresearchers

To ensure the equal involvement of PLWD, caregivers (and/or loved ones) and healthcare professionals, various approaches will be used to recruit coresearchers for the steering group. People from the patient advisory board of the DZNE in Witten and Bonn as well as from the DZNE Witten network, such as Dementia Leaders,[29] will be contacted. In addition, research group members have private networks, which they will contact to find coresearchers. Considering the focus on gender, sex and ethnicity, as well as the overall intersectional understanding of research in GenderDem, we want to ensure recruitment not only of different groups of people—such as people with dementia, their caregivers (and/or loved ones) or healthcare professionals—but also people eg, with different gender identities, of different ages and from different ethnic minority groups. By doing so, our sampling process aims to reflect our intersectional understanding of research by addressing the structural underrepresentation of marginalised groups in research.[25] The chosen strategy helps to provide a more equitable access to participatory research.

We aim to recruit a maximum of 10 coresearchers with at least two from each group of persons (people with dementia, caregivers and/or loved ones and healthcare professionals) and with a special focus on including people

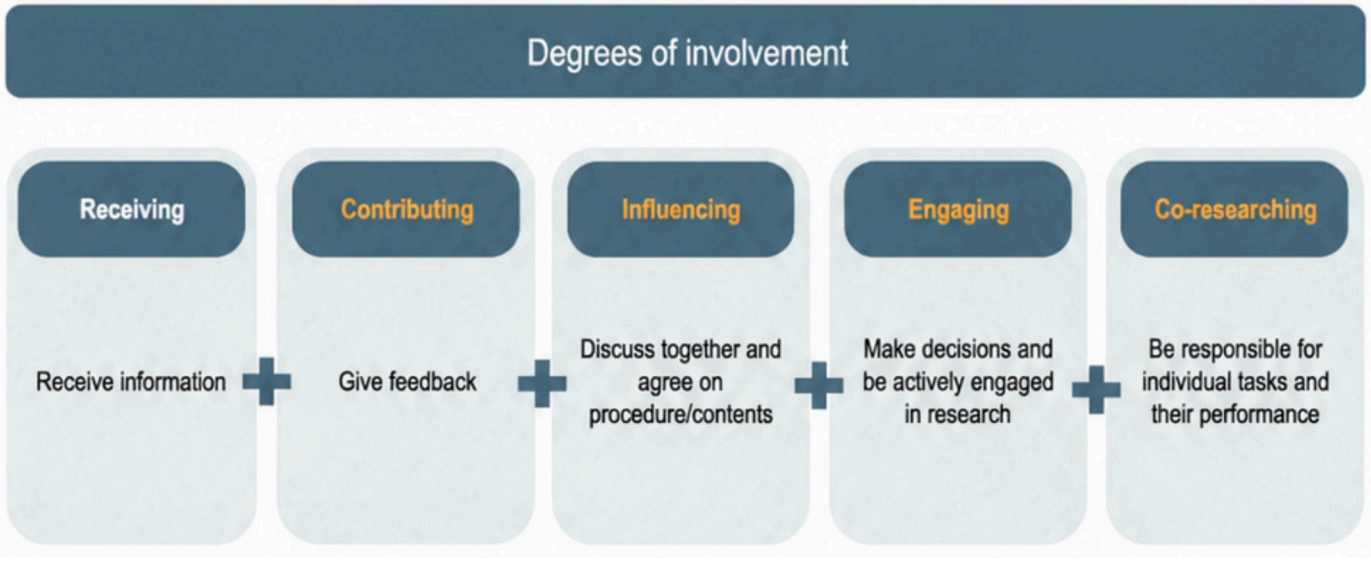

Figure 1 DECIDE SR–degrees of involvement.[27]

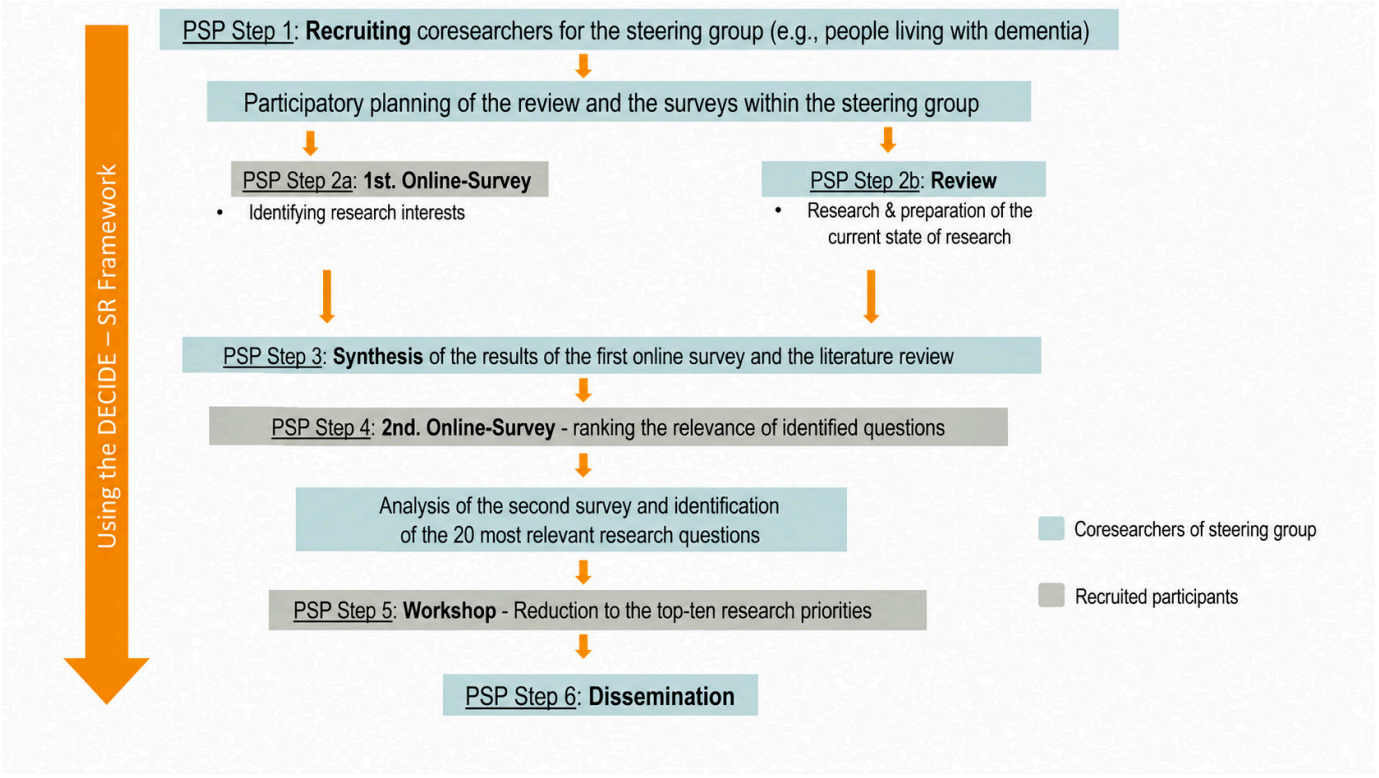

Figure 2 Methodological process GenderDem. PSP, priority setting partnership.

with various diversity characteristics. People throughout Germany can participate in the steering group.

Information on steering group participation will be provided by sending out flyers. To ensure an appropriate flyer design that meets the needs of our target groups, the flyer will first be tested with members of our local network of people with dementia and their caregivers (and/or loved ones). Modification requests will be considered.

We plan to hold virtual steering group meetings on a regular basis. The digital meetings of the steering group will provide the opportunity for people with various other responsibilities, for example, care responsibilities, to still participate.

Coresearchers will receive a coresearcher contract with the DZNE and an expense allowance (only people with dementia and their caregivers and/or loved ones).

PSP step 2a: first online survey

GenderDem aims to identify future research priorities regarding psychosocial interventions to address BPSD. Doing so provides the opportunity to express everyday challenges and questions related to the topic, so future research can be conducted in a way that is relevant to lived experiences.

To achieve this goal, an online survey via Lime-Survey (V.5.6.68+240625) will be conducted. The survey will be discussed and finalised by the steering group. By creating the survey together within the steering group, we will ensure that it is tailored to our diverse target group and designed to address the needs of all participants.

For the online survey, we aim to gather a targeted sample of PLWD, their caregivers and/or loved ones, healthcare professionals and researchers who have experience in dementia care. Including researchers in the surveys differs from the standard JLA methods. We will discuss this and any further adaptations of the method in our results paper. To reach as many people from these groups as possible, we will use various approaches to share the survey. First, the survey will be shared through the DZNE network and other partner organisations. A further list of possible gatekeepers has been created and will be updated continuously by the research team and the steering group. In addition, we plan to display flyers and posters with a QR code for the survey in various care settings (eg, adult day care services, hospitals) or medical practices (general practitioners, neurologists, psychiatrists) and expand the sample via social media channels (eg, DZNE accounts on Facebook and Instagram). Furthermore, the expertise of the coresearchers and their personal networks will be involved in sharing the survey. We hope that in these different ways, we will be able to reach a diverse group of people.

An overview of the sociodemographic characteristics included in the survey can be found in the online supplemental material (No.2). Given the focus on sex, gender and ethnicity sensitivity, the study participants will be asked to self-report on these characteristics. For example, regarding the focus on not only the biological but also the social gender, we decided on asking the participants which gender they identify with. The response options are

the following: male, female, divers, none, don't want to answer. These are based on current German law (Section 22, Article 3 of the Civil Status Act PStG). Regarding the focus on ethnicity aspects, we decided on asking multiple questions ranging from place of birth of the participants, their parents and grandparents to spoken languages at home. The questions are based on the question bank for sociodemographic data by the German data forum (RatSWD).[30]

Following the sociodemographic characteristics, the participants will be asked to describe the most important research topics for them regarding ideas about gender, sex and ethnicity-sensitive psychosocial interventions for dementia-related symptoms, specifically BPSD.

During the data-collection process, we will monitor the incoming surveys regarding the target group distribution (eg, people with migration history, different gender and sex identifications). By doing so, we will be able to identify any required adaptations to the recruiting strategy to reach a structurally similar distribution. We plan to start this process with approximately 100 complete surveys. Parallel to monitoring the answered surveys, we start the inductive qualitative evaluation using a qualitative content analysis.[31] As soon as signs of theoretical saturation appear, that is, when no new relevant findings are added, we will continue until 10 more surveys are completed. If no new topics emerge from these, the survey process will be considered complete.

The sociodemographic data of the participants will be evaluated using descriptive statistics in SPSS.

Once the survey has been completed, we will reflect on the methodological approach with the members of the steering group to determine whether conducting an online survey is an appropriate approach for our target group, or if we need to switch to qualitative interviews.

PSP step 2b: literature review

To identify the current state of the research and possible gaps, a literature review will be conducted parallel to the survey. The JLA proposes a systematic review for this purpose.[24] However, to obtain a sufficient impression of the current state of the research in our context, we will conduct an umbrella review.[32] By doing so, we can consider more information and findings from the current research (eg, scoping reviews, systematic reviews and meta-analyses). We will use the databases MEDLINE (via PubMed), CINAHL (via EBSCO) and PsycINFO (via Ovid). The full search string can be found in the online supplemental (No.3).

The exact research question for this review will be phrased by the steering group to establish a joint focus in the literature analysis. The search string will be developed and checked according to the PRESS criteria,[33] and the literature screening will include two members of the steering group supported by a member of the research team who will build tandems.[27] The screening process will be carried out independently to ensure the transparency and traceability of the selection.

PSP step 3: results synthesis

After the first survey and the umbrella review are completed, the results of both will be evaluated and compiled with the coresearchers from the steering group. Doing so allows us to compare the topics or questions from the survey with the review results and thus identify topics that appear to be relevant to the affected parties that have not yet been addressed in the research. Topics and questions from the survey that have already been addressed and answered by our review will be removed.

Following the JLA method, the questions and themes the participants answered in the first survey will be reviewed and clustered by emerging themes. These clustered questions and themes then will be compromised to summarised questions, needed for the second survey.

For each emerging theme, we will form research questions addressing sex, gender and ethnicity for PLWD showing BPSD.

PSP step 4: second online survey

The aim of the second online survey is to identify the 20 most important research topics or questions. To achieve this goal, we plan to use the same strategy as explained for the first survey. Doing so entails using the same recruitment strategy for participants. If participants from the first survey agreed to be contacted and provided information, they will be contacted again. By monitoring the responses, we can make adjustments if necessary to represent all target groups appropriately.

The characteristics mentioned in the first survey will be included. Following these sociodemographic questions, the participants will be asked to rank the research topics or questions (PSP step 3) in terms of relevance using a 4-point scale ('strongly disagree', 'disagree', 'agree' and 'strongly agree'). Beforehand, the steering group will agree on the number of topics or questions to be included in the second survey. The sociodemographic data and the individual rankings of the participants will be evaluated using descriptive statistics in SPSS. These results will lead to the identification of the top-20 research topics or questions from the different target groups.

PSP step 5: workshop

The goal of the workshop is to identify the top-10 research priorities (of 20) for gender, sex and ethnicity-sensitive psychosocial interventions to manage dementia-related symptoms in people with dementia.

Following the JLA guideline,[24] this prioritisation step will take place during a participatory workshop. PLWD, their caregivers and/or loved ones, healthcare professionals and researchers will be recruited as participants to discuss future research priorities. We will ask the participants from the two online surveys whether they are interested in participating in this workshop and reach out to those who agreed to be contacted. Furthermore, DZNE networks and partner organisations as well as the members of the steering group will recruit participants for the workshop. We aim to involve a maximum of 20

people with at least four members from each group of persons (PLWD, their caregivers (and/or loved ones), healthcare professionals, and dementia researchers).

The workshop will take place in a hybrid form to facilitate people who would not be able to participate in the workshop in person. In addition, the workshop will take place at an easy-to-reach and accessible place. There will be regular breaks, and participants will be informed that they can pause or discontinue their participation at any time without any disadvantage. Retreat rooms will be available.

During the workshop, first, steering group members will give a short presentation about the project GenderDem, the identified top-20 research topics or questions and the steps required to identify the top-10 priorities. All participants will be equally informed.

The JLA suggests five phases for small group discussions in the workshop: (1) small groups initially rank the priorities, (2) the whole group reviews these rankings, (3) new small groups are formed to further discuss priorities from the first round, (4) small groups engage in a second prioritisation and (5) the whole group prioritises the top-10 research priorities.[24] We will discuss this suggested procedure in the steering group and adapt it for our target group, if necessary.

ETHICS AND DISSEMINATION

Alzheimer Europe[34] and the European Working Group of People with Dementia[35] emphasise the inclusion of people with dementia as members of advisory boards and coresearchers. These organisations note, coresearchers do not require ethical clearance (since no data will be collected and they are part of the research team). However, an ethics application for conducting the two online surveys and the workshop for this study has been approved by the German Society of Nursing Science (No. 25-029). In addition to the two online surveys, interviews with PLWD are planned. Conducting ethical clearance on the basis of one identifying characteristic (diagnosis of dementia) of any coresearcher would be viewed as a form of discrimination and stigmatisation.[36] During the entire research process, we will use respectful terminology and avoid any harmful or stigmatising speech (eg, person living with dementia instead of dementia sufferer).[37] During all of the study phases, PLWD, caregivers (and/or their loved ones) and healthcare professionals will be involved, either as part of the steering group or as survey and/or workshop participants. In particular, PLWD but also their caregivers (and/or loved ones) can be vulnerable because of cognitive limitations and/or stress resulting from their caregiving responsibilities[38] that can be exacerbated by their tasks as coresearchers. Furthermore, we will pay attention to any signs of overload, critical situations or emotional stress among the participants. In addition to the measures already mentioned to ensure that participants are informed about the voluntary nature of participation and all relevant study steps, this point is relevant regarding the informed consent process in relation to our target group and its associated complexity.[39]

By planning all parts of the research process within the steering group and therefore together with experts in everyday life with dementia, we will be able to adapt the survey design and the workshop organisation according to the possible needs of our target group.

Together with the coresearchers from the steering group, we will develop a dissemination plan that considers the different media consumption forms of the various groups and we will disseminate our project results accordingly on an ongoing basis.

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Contributors EM wrote the initial draft of the protocol. GY, KA, SAF, CM, MR-M and MR revised the manuscript. MR-M coordinated this study. MR initiated the study and is the principal investigator. All of the authors read and approved the final manuscript. MR acted as guarantor.

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