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Lessons learned from the participatory development of a framework to actively involve people living with dementia, individuals from their social networks, and healthcare professionals in systematic reviews: the DECIDE-SR study

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Abstract

Background To date, there is no framework for actively involving people living with dementia, individuals from their social networks and healthcare professionals in systematic reviews (SRs). Additionally, no SRs have been planned or partially carried out with the active involvement of these individuals. For these reasons, a framework and a review protocol for a planned SR were developed as part of the federal-funded DECIDE-SR project, in which the abovementioned groups were actively involved as coresearchers. The purpose of this paper is to provide an overview of the project and to illustrate the lessons learned from conducting active research involving this case example.

Methods A framework for actively involving coresearchers in SRs was developed via the synthesis of theoretical and empirical findings from a previous research project. The coresearchers participated in meetings and one workshop, which were planned on the basis of the INVOLVE criteria and the ACTIVE framework model, to test and reflect on the previously developed framework. Additionally, an SR protocol was jointly planned during these meetings, and individual SR steps were conducted (e.g., development of the research question). The lessons learned were drawn from the workshop with the coresearchers, who were clustered using the Engaging with Purpose Patient Engagement Framework (EwPPEF).

Results Eight coresearchers were actively involved in 15 meetings and one workshop to test and reflect on the framework. The framework allows coresearchers to individually choose their own level of involvement (where the levels are nonhierarchical), and the individual support needs at each step of an SR are considered. Additionally, an SR protocol was developed together with the research question "What is the effect of hospital treatment provided

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in one's own living place on people living with dementia?". The lessons learned provide information on all aspects of the EwPPEF (e.g., cobuilding, impact, and inclusiveness) and include implications for conducting SRs that actively involve the public.

Conclusions The framework and the SR protocol can now be used for further tests and to gain initial experience in conducting SRs that actively involve the public. Furthermore, the lessons learned can provide other project groups with important insights into actively planning and conducting SRs.

Keywords Framework, Participatory research, Collaboration, Public, Dementia

Plain English summary

Systematic reviews (SRs) are of critical importance to professionals and people who make decisions in health care. In contrast to other research approaches, no approach for actively involving people living with dementia, individuals from their social networks, and healthcare professionals in SRs exists. Furthermore, no review that actively involves these groups has been conducted. To change this, an approach for active involvement and a review protocol for a planned SR were developed as part of the federal-funded DECIDE-SR project. This article provides an overview of the results of the project and illustrates the lessons learned. The approach for actively involving these groups was developed on the basis of the findings of a previous research project and was tested and reflected upon with the coresearchers during meetings and one workshop. Moreover, a review protocol was jointly developed with the coresearchers during the meetings, and some SR steps were jointly conducted (e.g., development of the research question). In the workshop, lessons learned from the project were jointly determined in discussions with the coresearchers and were categorized. The approach and review protocol can now be used to gain initial experience in conducting SRs that actively involve people living with dementia, individuals from their social networks, and healthcare professionals. Additionally, the lessons learned from the project can provide others with important information for future projects that focus on SRs that actively involve the public.

Background

The active involvement of the public in healthcare research can be a key aspect of successful research [25]. Active involvement is particularly important, for example, when conducting research that addresses the needs and challenges of the people for whom the research is intended. This reflects the motto"People who are affected by research have a right to have a say in what and how publicly funded research is undertaken"[17]. This consideration of lived experiences as a result of the active involvement of experts may produce research results that lead, for example, to health-care solutions that are adapted to people's living experiences and therefore have a greater chance of successful implementation [29, 41, 43].

Since the 1980 s, efforts have been made to increase the awareness of researchers regarding the importance of actively involving the public in research. Furthermore, attempts have also been made to further improve the active involvement of the public, e.g., as an evaluation criterion for research funding applications [22]. As a result of the frustration felt by and criticism from the indigenous population in the USA, who were"researched to death"by academic researchers conducting"helicopter research", various research projects carried out from the 1990 s onward actively involved individuals affected by the research, for example, people with cancer, diabetes, or mental illness, as coresearchers [2, 5, 12, 22]. This active involvement can range from generating research ideas, advising researchers, and taking part in consultations to direct involvement in research activities such as the collection and analysis of data [11, 19]. To support this type of research approach, the National Institute for Health and Care Research developed briefing notes for researchers in 2012, which provide guidance on what needs to be considered in research with active public involvement [17].

Currently, most research projects with active public involvement appear to focus primarily on people without cognitive impairment. A simple literature search in MEDLINE makes it clear that when considering groups other than coresearchers (e.g., people with cancer), there are not only fewer studies involving the implementation of a research approach with the active participation of people with dementia, but research in this area also began later (1678 records in 1988–2024 versus 362 records in 1997–2024). At first glance, this does not seem surprising, as people living with dementia are often socially stigmatized and deprived of their personality and autonomy owing to the possible and well-known symptom of memory loss, among other things [13, 28, 40]. This prejudgment seems to also be evident among researchers, who assume that the accounts of people living with dementia are not reliable [11, 20]. In recent years, it has been possible to overcome this barrier by increasing the awareness of this topic among researchers in the field of dementia care and disseminating the first practical research experiences that actively involve people living with dementia [6, 11, 20, 36]. This has led to a steady increase in the number of publications on this topic since 2017, as shown by a simple literature search in MEDLINE (25 records from 2017 versus 63 records from 2023). This makes it clear that people living with dementia are able and interested in being involved in all stages of the research process [26, 35]. To make this happen, various prerequisites appear to be important. For example, relationship building between coresearchers and professional researchers is described as an important aspect of success in actively involving people living with dementia in the research [11, 24, 44]. In this context, mutual trust, respect, and a feeling of physical and emotional safety can be summarized as a requirement/basis for a professional relationship [11, 24, 36]. Building relationships can be fostered, for example, by listening to these individuals, providing them with opportunities to meaningfully contribute to the research (e.g., equal power), recognizing them as people with stories to tell, giving them credit for their contributions and the opportunity to provide "honest" feedback and criticism, supporting them when needed, not overprotecting or patronizing them, and providing them with clarity about the requirements and skills needed for the various research tasks [3, 11, 20, 24, 35, 44]. Furthermore, Rivett [34] in her scoping review of existing general principles, described how people living with dementia can effectively and safely be involved in research. This includes using clear and accessible language when talking about research, allowing time to think and respond, using individualized visual prompts for support, and discussing the location and time of meetings. Additionally, it can be helpful/necessary to involve caregivers and relatives in the research to supplement the perspective or to support the person living with dementia [34].

Current projects with the active involvement of people living with dementia focus, for example, on healthcare and social intervention developments and the evaluation or implementation of these interventions [1, 3]. Other than these research projects, few systematic reviews (SRs) seem to actively involve people living with dementia in the research [31, 33].

Systematic literature reviews are an important source of information for professionals and (political) decision-makers in the healthcare system [14]. As a summary of different studies and an evaluation of the effectiveness of, for example, the complex interventions tested in these studies, SRs are considered a form of external evidence and are therefore an essential part of evidence-based decision-making in healthcare [9, 23, 37]. Consequently, the results of systematic reviews can have a direct effect on the health and care of people receiving acute care or long-term services and support and can influence the financing of complex interventions by (political) decision-makers [14]. Although people living with dementia have been excluded from active participation in research, many different public groups (e.g., people with cancer, mental illness, and carers) have been involved as coresearchers in SRs. This active involvement ranges from setting scope/review questions throughout/within the review process or interpreting results after the review [31].

In view of the points mentioned above and to further develop and discuss the active involvement of people living with dementia in research, actively involving people living with dementia as coresearchers in SRs alongside other public groups involved in SRs is urgently important. As a result, in the federal-funded DECIDE-SR project (Grant No. 01 KG2213), we developed a framework for conducting an SR that actively involves people living with dementia, individuals from their social networks, and healthcare professionals, who test and critically reflect on the framework as coresearchers. In addition, we developed a review protocol together with the coresearchers and conducted some of the steps from the planned SR (e.g., development of the research question).

Overview of the DECIDE-SR Project

To provide an overview of the DECIDE-SR project and the lessons learned and to ensure rigor, we followed the short version of the Guidance for Reporting Involvement of Patients and the Public (GRIPP2) checklist: a tool to improve the reporting of patient and public involvement in research (Supplementary Material 1) [45]. A detailed description of the plan for the DECIDE-SR project, including a timetable and milestones, is described in our study protocol [38].

Preparation and recruitment

After the funding application was approved and before we started the DECIDE-SR project, which had a one-year duration (2022–2023), we recruited people for our international advisory board. A total of six international experts were recruited from the research network of the German Center for Neurodegenerative Diseases (DZNE) Witten site for the advisory board. All six researchers were characterized by their expertise in the field of active involvement and engagement research with older people and/or people living with dementia. The advisory board accompanied the project, and an exchange and critical reflection on the respective (partial) results took place during and at the end of the project period. We recruited the coresearchers for our project from the patient advisory board of the DZNE and our practice partners from acute or long-term care and support services. For this purpose, online information events were organized via Zoom, in which details such as the objectives and schedule of the project were presented. As the project goal was to engage a small heterogeneous group of coresearchers working on a topic that unites/concerns them and the time frame was limited to one year, we kept the project team of coresearchers small on the basis of previous experiences (e.g., facilitating relationship building and responding to individual support needs). Therefore, the aim was to recruit six people as coresearchers. Eight people, including a person with dementia and various health care professionals (e.g., physicians, registered nurses, advanced nurse practitioners, quality managers, and hospital directors of nursing), expressed interest in participating in the project as coresearchers.

Ethical aspects and initial development of the framework

Ethical aspects of the DECIDE-SR project regarding, for example, the active involvement of people living with dementia as coresearchers are discussed and reported in detail elsewhere [38].

In parallel with recruitment, we developed a framework for active involvement in systematic reviews by summarizing the theoretical [10, 32] and empirical findings from a previous active involvement research project (PREBEDEM Grant No. 01 KX2230) [16] involving people living with dementia, individuals from their social networks, and healthcare professionals. This led to a preliminary version of a framework that contains nonhierarchical degrees of involvement, from which coresearchers can select their individual degree of involvement in the various steps of an SR (e.g., development of the research question, conducting title and abstract screening) (Fig. 1). The development of this preliminary version of the framework was necessary to facilitate work with the coresearchers in the upcoming joint meetings and the workshop (e.g., in the development of the review protocol).

The meetings

We conducted 15 90-min meetings via Zoom and one in-person workshop to allow the recruited coresearchers to test and reflect on this framework and to develop the review protocol. The meetings and workshop were based on the INVOLVE criteria, and an adapted version of the ACTIVE framework was employed to structure the meetings [17, 18, 32]. To support communication and relationship building in the group, to ensure that a sense of trust was experienced by all, and to ensure that all coresearchers were able to develop the courage to express themselves freely in the group, we started each meeting with the questions “Is there anything you want to share with the group before we start with our meeting?” and “Do you have any questions regarding the last or today’s meeting?” Furthermore, we organized the meetings thematically according to the individual steps of an SR (e.g., development of the research question and conducting the screening process) and divided them into two sessions. In the first session of each meeting, we presented the methodological and content-related aspects of each step of the systematic review to the coresearchers. We explained the content, words, tasks, and goals of each step of the systematic review in a simple way to ensure understanding by all coresearchers (Fig. 2). We then discussed the content and clarified any open questions. For further information, see our study protocol [38].

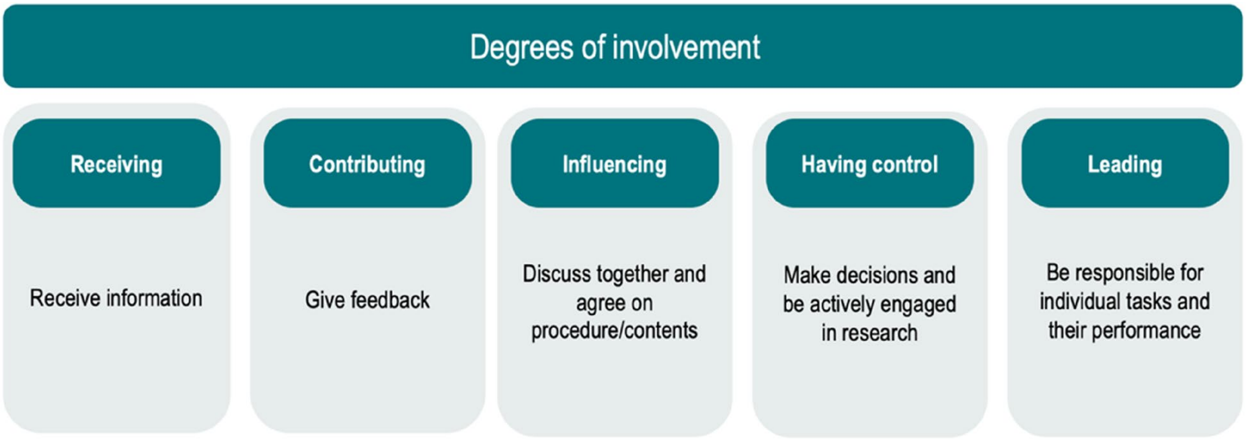
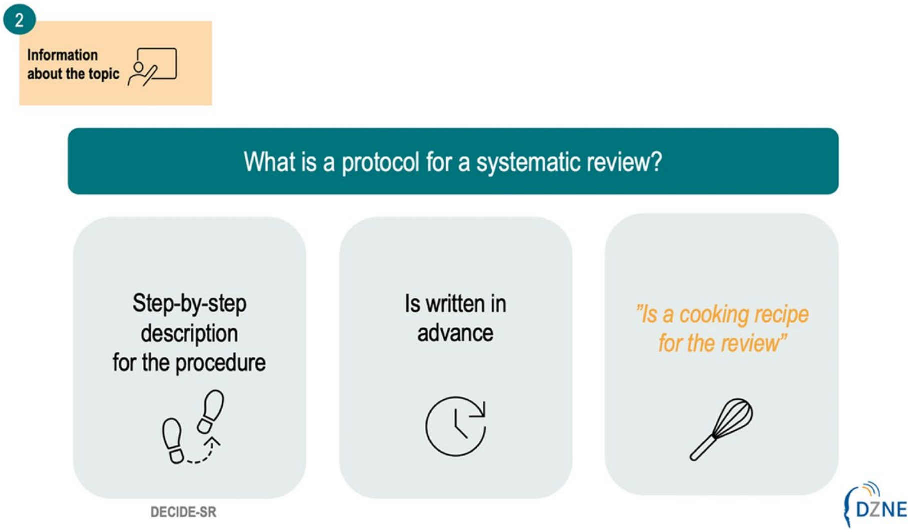


Fig. 1 Preliminary framework for active involvement in systematic reviews



2

Information about the topic

What is a protocol for a systematic review?

Step-by-step description for the procedure

Is written in advance

"Is a cooking recipe for the review"

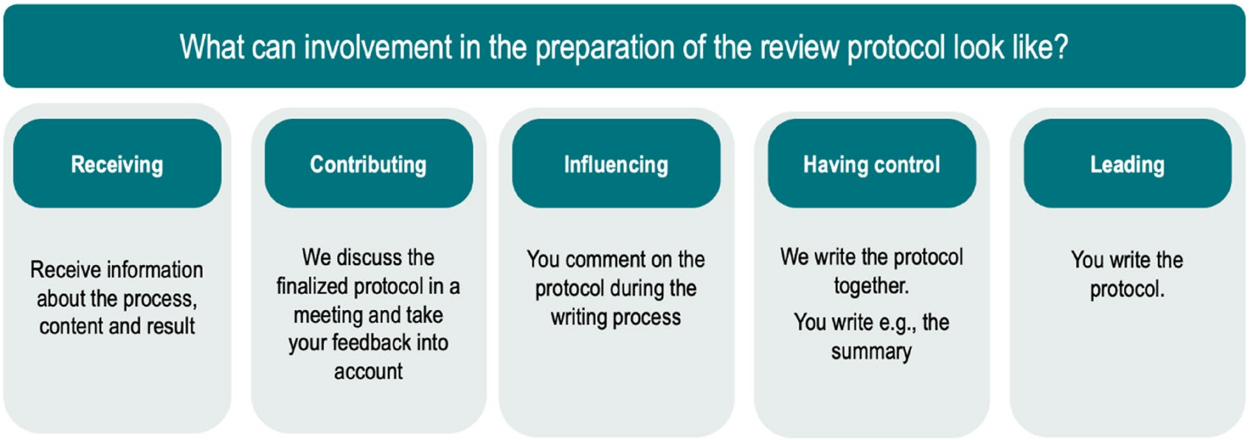
DECIDE-SR

Fig. 2 Example of an "information about the topic" slide [38]

Each coresearcher then had the opportunity to choose their involvement in the planning/conducting of the SR step according to their individual preferences and skills. For this purpose, we used our preliminary framework and adapted it according to the respective step of the SR so that the coresearchers were directly informed about what the respective degree of involvement meant in the context of the respective step of the SR (Fig. 3).

The corresponding support needs of the coresearchers for the realization of their chosen involvement (e.g., training in the use of screening software, partners for writing the protocol) were subsequently assessed via a survey and considered for the second part of the meetings. As an example, if 'influencing' was chosen as the degree of involvement during the review protocol writing step, we asked them which methods they suggest for supporting this process, such as training in the use of Microsoft Word, the publication guidelines of different journals, or the requirements of protocols based on the relevant reporting guidelines. Consequently, the support was always aligned with the respective step of the systematic review and was reassessed and adapted to the coresearcher's needs for each subsequent step [38].

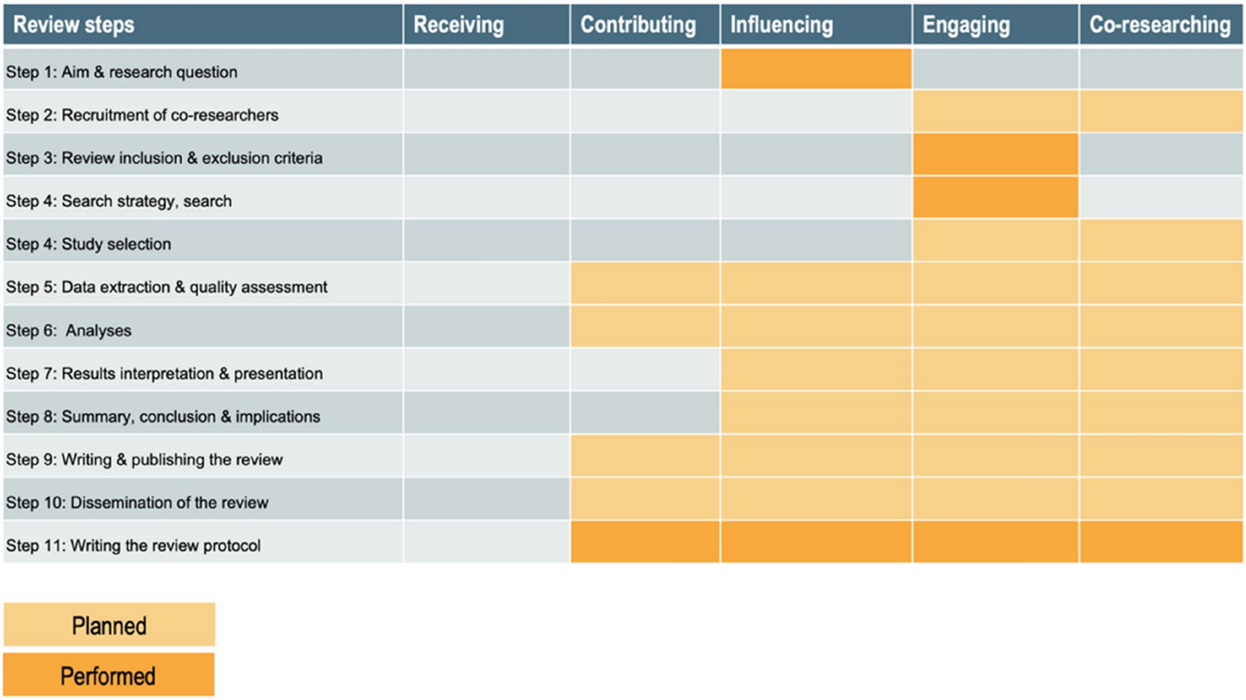
For the second part of each meeting, the coresearchers were then actively involved according to the chosen degree of involvement (e.g., development of the research question, test screening titles and abstracts, and determination of the analysis method). Figure 4 shows the degree of involvement of the coresearchers in the completed steps (steps 1, 3, 4, and 11) and the planned steps (steps



What can involvement in the preparation of the review protocol look like?

Receiving	Contributing	Influencing	Having control	Leading
Receive information about the process, content and result	We discuss the finalized protocol in a meeting and take your feedback into account	You comment on the protocol during the writing process	We write the protocol together. You write e.g., the summary	You write the protocol.

Fig. 3 Preliminary framework for active involvement using an example of protocol preparation



Review steps	Receiving	Contributing	Influencing	Engaging	Co-researching
Step 1: Aim & research question			🟧		
Step 2: Recruitment of co-researchers				🟨	🟨
Step 3: Review inclusion & exclusion criteria				🟧	
Step 4: Search strategy, search				🟧	
Step 4: Study selection				🟨	🟨
Step 5: Data extraction & quality assessment		🟨	🟨	🟨	🟨
Step 6: Analyses		🟨	🟨	🟨	🟨
Step 7: Results interpretation & presentation			🟨	🟨	🟨
Step 8: Summary, conclusion & implications			🟨	🟨	🟨
Step 9: Writing & publishing the review		🟨	🟨	🟨	🟨
Step 10: Dissemination of the review		🟨	🟨	🟨	🟨
Step 11: Writing the review protocol		🟧	🟧	🟧	🟧

🟨 Planned

🟧 Performed

Fig. 4 Degrees of involvement in the planned systematic review

2 and 5–10) of the planned SR with the jointly developed research question"What is the effect of hospital treatment provided in one's own living place on people living with dementia?".

At the end of each meeting, challenges in the respective session were discussed, and the framework was critically reviewed with the coresearchers in relation to its utilization. This included, for example, discussions of the examples chosen to explain the various examples for the choice regarding the degree of involvement, the wording, and the graphic presentation. The answers were recorded and stored for later evaluation. A more detailed description of this methodological process is reported elsewhere [38].

Workshop and finalization of the framework

In the final workshop with the coresearchers, we met in person, reflected on the results of the individual workshops (e.g., finalized review protocol) and evaluated the framework used to determine the individual involvement of the coresearchers in the individual steps of the SR. As a result, we adapted the framework by changing the names of the individual degrees of involvement. This adjustment was made on the basis of feedback regarding the previous names, which were considered too complicated and misleading (Fig. 5).

We also summarized and visualized the entire process of using the framework, which also includes the identification of the coresearchers'support needs, in a workflow (Fig. 6).

Finally, we discussed and recorded the lessons learned from our collaboration, the progress of the project, the external requirements influencing our project, the results of our work and possible future collaborations. This was necessary because, in addition to providing a structured framework for the involvement of coresearchers, e.g., people living with dementia, in SRs and a review protocol for a planned SR, our aim, as the DECIDE-SR project group, was also to communicate the lessons learned in relation to collaboration between nonprofessional and professional researchers in the scientific environment.

Lessons learned from the DECIDE-SR project

To report on the lessons learned, we extracted the relevant content using the meeting and the workshop protocols. Additionally, the professional researchers met several times regarding the project completion and the application for the follow-up proposal. We discussed and included further lessons learned, particularly in relation to structural aspects, cooperation with external organizations, the competitiveness of research with active involvement in the context of the scientific community, and challenges when applying for grants.

To communicate these lessons learned in a structured way, we organized all the extracted points according to the various aspects of the Engaging with Purpose Patient

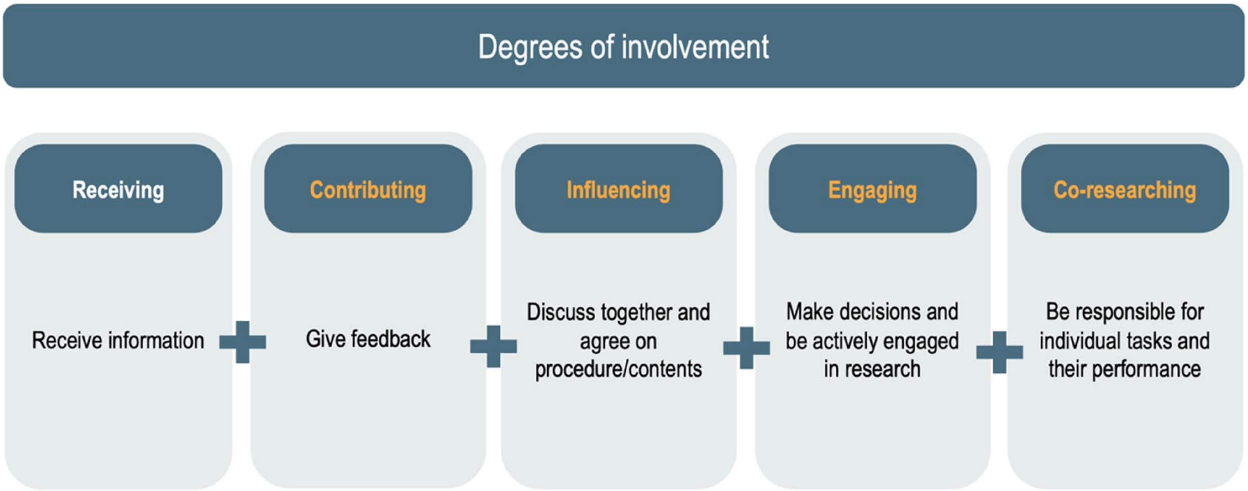


Fig. 5 Updated framework for active involvement in systematic reviews

Engagement Framework (EwPPEF). The EwPPEF is based on a sentiment analysis of various Twitter tweets under the hashtag #HowToDoPatientEngagement and #HowNotToDoPatientEngagement. These tweets were analyzed via thematic analysis, which led to the following five key pillars of meaningful research with active involvement: cobuilding, impact, support, mutual respect, and inclusivity [8].

Lessons learned: Cobuilding

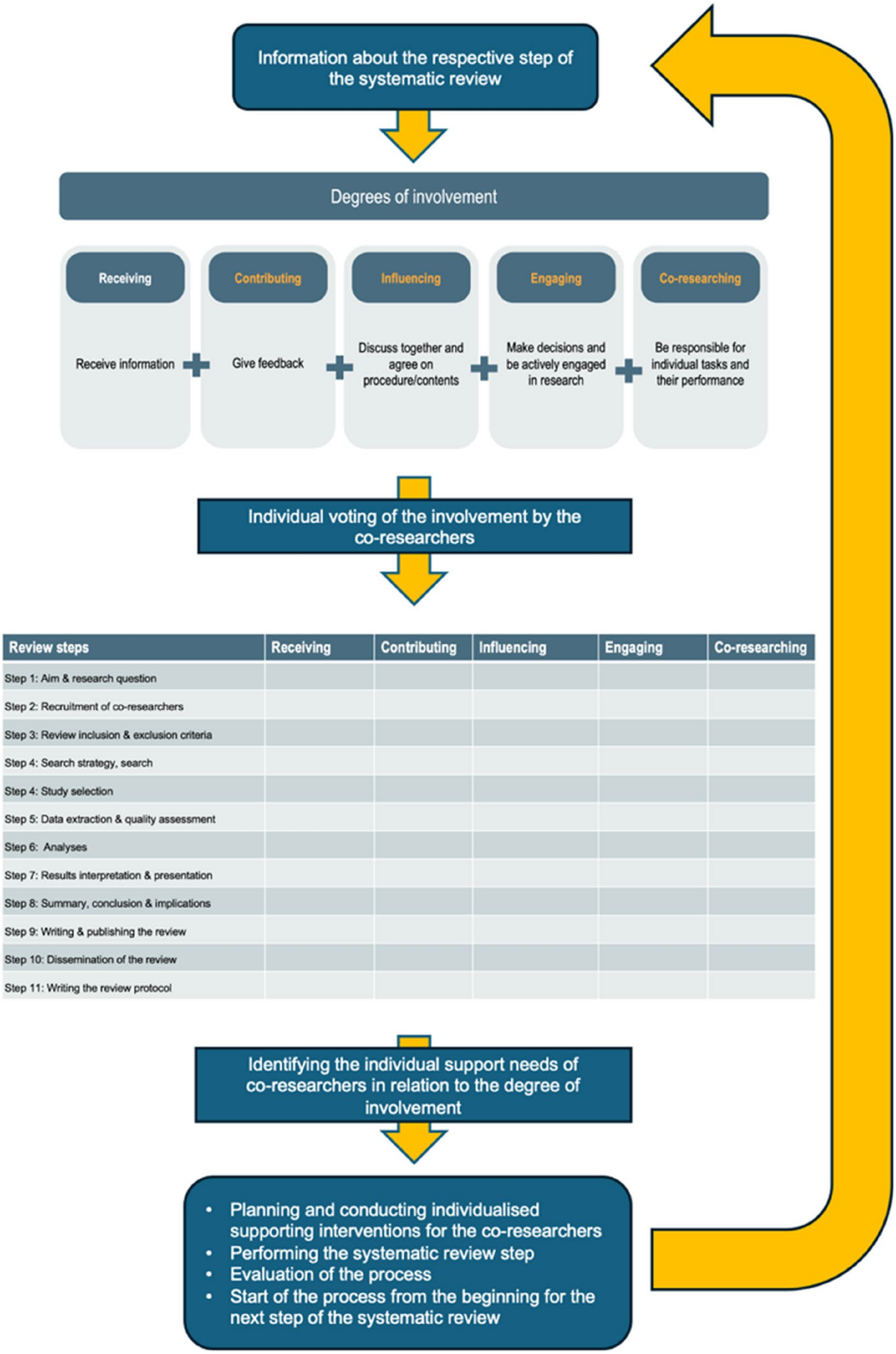
We found that using our framework and thus providing coresearchers with the possibility to define/choose their degree of involvement and engagement was a viable and good way to consider their preferences and skills for all stages of research with active involvement. Specifically, this provided the coresearchers with the opportunity to be actively involved in all the steps of planning/conducting a systematic review, which was an important concern for us as a group of coresearchers and professional researchers.

Despite the active involvement of individual coresearchers in the grant application for the DECIDE-SR project, not all participating coresearchers were involved in this step. This was because at the time of submitting the proposal, we had not defined or recruited all coresearchers. As a result, we established an ongoing recruitment process for each new research project, which was partly performed before and after successful grant application and approval. The recruitment of coresearchers takes a great deal time and is subject to the time pressure of the respective project duration, especially with respect to the recruitment of people living with dementia and those from their social network. On the basis of our experience, building relationships, building teams, and breaking down barriers and prejudices between coresearchers and professional researchers are essential for cobuilding but are also time intensive [20]. Given the general funding period for research projects in Germany and the fact that initiating and establishing an ongoing relationship with coresearchers is (usually) not part of individual project funding, this appears to be a barrier for actively establishing public involvement in dementia care research [30].

Furthermore, we learned that research with active public involvement is not limited to professional cobuilding. The close collaboration between coresearchers and professional researchers can also include the discussion of private topics during the meetings. Consequently, this can lead to connections via social media, for example, and professional researchers become part of the social environments of the coresearchers. Here, it seems necessary to establish common rules as a research group in advance and to clarify to what extent this “closeness” is acceptable to each individual. In our meetings, we used the first 15–20 min to talk about current situations/events or acute illness experiences. This was found to be a good way to “start the meetings” for everyone involved and to make a clear distinction between private aspects and professional work.

Lessons learned: Impact

We learned that the lived experiences of our coresearchers significantly impacted the various planning/conducting steps of the SR and thus led to unexpected outcomes from a purely scientific point of view. This was particularly noticeable in the formulation of the research question and, thus, the specification of the topic. This led, for example, to the term ‘hospital at home’ being critically



Review steps	Receiving	Contributing	Influencing	Engaging	Co-researching
Step 1: Aim & research question					
Step 2: Recruitment of co-researchers					
Step 3: Review inclusion & exclusion criteria					
Step 4: Search strategy, search					
Step 4: Study selection					
Step 5: Data extraction & quality assessment					
Step 6: Analyses					
Step 7: Results interpretation & presentation					
Step 8: Summary, conclusion & implications					
Step 9: Writing & publishing the review					
Step 10: Dissemination of the review					
Step 11: Writing the review protocol					

Fig. 6 Workflow for using the framework for active involvement in systematic reviews

discussed by the coresearchers and the group deciding in favor of the term ‘hospital treatment at their own living place’, which is different from the usual scientific term for this intervention. Additionally, we included other care settings, such as nursing homes, in our planned SR, as these settings were also defined by the coresearchers as “one’s own living place”. As a result, further search terms for interventions and care settings were added to the developed search string. Thus, the field of hospital treatment in one’s own living place was expanded on the basis of the lived experiences of coresearchers.

Another example of this impact of the coresearchers was evident in the selection of the primary and secondary outcomes for the SR. Accordingly, outcomes that have thus far received little, if any, attention as secondary outcomes in research on this topic were considered important by the coresearchers. Thus, the following primary outcomes were determined by the group, contrary to what has been scientifically established to date: independence, quality of life, and cognition versus mortality, transfer, and readmission [42]. In particular, the focus on other outcomes on the basis of the lived/professional experiences of the coresearchers provides the opportunity to impact other researchers and their research (e.g., randomized controlled trials) and not only on SRs.

Additionally, we see a critical view of the scientific community on the impact of active involvement in all and/or clear standardized processes of an SR, such as conducting data extraction [30]. We observed that the active involvement of coresearchers in the definition and specification of the aspects to be extracted, in addition to those already standardized by guidelines [15, 27], certainly appears to have an impact. However, with respect to extracting data, a critical reflection on the impact and the time and financial resources required by coresearchers for this step seems necessary. This is because the influence of the lived/professional experiences of the coresearchers should not have an impact on the results of these standardized review procedures. However, during the planning/conduction of the SR, we learned that all coresearchers also expressed interest in actually planning/conducting the data extraction, and it was important to do this on their own and/or together with a professional researcher. This raises an ethical question regarding research with active involvement in the context of power between participants and limited resources. In our view, contrary to the Cochrane Consumer Network’s brief guide [4], the aim and purpose of research with active involvement cannot be to make the active involvement of coresearchers solely dependent on the decisions of professional researchers and/or based on financial/time constraints. Consequently, the degree of involvement in each step of the research process always needs to be negotiated or agreed upon. We have learned that this is a way to ensure that a balance of power is established within the group and that coresearchers are not “used” only when its “suits” professional researchers.

Finally, one aim of the DECIDE-SR project was to continue to work together as a group, with the possibility of further funding to conduct the review (follow-up). To this end, the coresearchers worked intensively on the topic of “hospital treatment in one’s own living place”, jointly prepared the review protocol, and were involved in developing the follow-up proposal. However, two events impacted our next steps: (1) a recent SR on our chosen topic with a more general view of geriatric patients and without active involvement of people living with dementia and other professional stakeholders was recently published [21] and (2) the reviewer of the follow-up proposal considered the topic with a sole focus on people living with dementia to be too narrow (e.g., limited number of identified studies), which led to no funding for the follow-up proposal. This outcome led to great disappointment and a pause in our collaboration with the coresearchers. This raises some ethical questions. For example, who should address the feelings of the coresearchers and how can they be addressed? Consequently, it seems essential for research organizations, such as the DZNE/Witten site, who are in the process of establishing structures for research with active involvement to receive sufficient support. Accordingly, research with active involvement cannot be measured/evaluated solely on the basis of effectiveness in the development/finalization of a “product”.

Lessons learned: Support

In terms of support, we learned that it is important to identify the individual support needs of coresearchers depending on their level of involvement. This support was highly individualized, depending on the respective skills and preferences of the coresearchers, and ranged from providing virtual meetings on how to use software, introducing research and the content aspects of an SR, and providing aids such as a reference book for the most important terms or working together in tandem (professional researcher/coresearcher). In particular, the support provided in the form of tandem working proved beneficial for the preparation of the review protocol. After agreeing who would write which section (e.g., summary, background, methods, or discussion), the four teams were able to work closely and in a coordinated manner. In addition, the virtual meetings made it possible for the entire group, which are located in different parts of Germany, to participate in a low-threshold manner. This means that participation was possible using a smartphone or tablet, and, for example, costs and travel to meeting locations could be avoided for coresearchers. The ability to use technology is highly individual and independent of the background of the coresearcher. This ability should be ascertained in advance to determine whether participation in virtual meetings requires support, assessing digital literacy is of high importance (Hannemann et al., 2023). In our case, all the coresearchers participated in the virtual meetings independently without support. We learned that the documents for each meeting should be sent as early as possible (e.g., 14 days in advance) so that all researchers can prepare for the next meeting at their own pace. Furthermore, it was particularly important for the person living with dementia that these meetings took place in the late afternoon and not in the morning. This time was also easier for practitioners to plan and was therefore favored. We also observed that the coresearcher contracts with the DZNE, financial remuneration, and etiquette, which were determined/defined in advance, had a positive effect on the empowerment/power of the coresearchers and on the group as a whole and created a safe space for everyone to work together. As a group, we experienced that the collegial interaction created by the previously defined rules/equalization of the balance of power meant that all members of the group supported each other. When difficulties/challenges arose within the group, it was important that a person was selected in advance who would be responsible/responsive with respect to these issues. Finally, we learned that the supporting aspects in particular are associated with a great deal of time and costs, especially if a “top and tail” approach (active involvement at the beginning and end of the research project) to the active involvement of coresearchers is not employed [4]. Here, it seems essential to develop a detailed plan with coresearchers in advance and thus during the project application, including thoughts on incentives for coresearchers, materials needed, and software and hardware costs.

Lessons learned: Mutual respect

We found that professional researchers must reflect on their own habitus, use common language, and develop a welcoming attitude to create a respectful research environment for everyone “on board”. In our meetings, we learned that this was essential for supporting the self-confidence of the coresearchers and, thus, for promoting respectful and supportive communication. In addition, it was beneficial when professional researchers and coresearchers shared the same professional background (e.g., registered nurse). This resulted in a common language and the opportunity for shared experiences with the coresearchers. We also learned that it is conducive to respectful interaction if a moderator leads meetings with a view toward requests to speak and thus ensures that everyone has an equal say. This included, for example, actively encouraging requests to speak and directly addressing people from the group (coresearcher/professional researcher) who would otherwise often hold back while not pressuring them to speak and showing appreciation for comments and taking them into account. Additionally, the first 15–20 min of personal exchange in each meeting created a group dynamic that promoted respectful interaction and a culture of discussion. Thus, in addition to the scientific/research skills and time management skills, a high degree of self-reflection, moderation, and social skills are needed. Otherwise, it can lead to the development of a workflow in which coresearchers are intimidated and only agree with the opinions of the ‘loudest’ person and/or the person with the highest professional status (professor/doctor). On the basis of our experience, preparatory training for professional researchers as well as resources (e.g., financial) to continuously support coresearchers are needed. Furthermore, establishing an exchange between experienced and inexperienced national/international organizations in participatory dementia research as well as establishing long-term collaborations with a variety of public representatives (e.g., the European Working Group of People with Dementia (EWGPWD)) must be financed accordingly.

Lessons learned: Inclusivity

During the DECIDE-SR project, the time available for recruiting coresearchers was limited to a very short period. This proved to be a particular challenge when recruiting people living with dementia. As a result, we were only able to recruit one person with dementia as a coresearcher. In addition, we learned that it is particularly important for people living with dementia to be in a “well-being phase” to address an additional topic, such as the role of a coresearcher. In combination with the possible experience of social stigmatization faced by people living with dementia, the progression of the disease combined with multimorbidity, underrepresentation of diverse populations in dementia care research, and the lack of structures and processes to become actively involved in dementia care research in Germany appear to be major barriers to identifying and conducting inclusive dementia care research.

Accordingly, we learned that the recruitment of relatives of people living with dementia poses further challenges. Questions arose as to who would take care of the person living with dementia while the relative was attending a meeting or workshop if the person living with dementia was not involved. Moreover, the burden (e.g., caring for people living with dementia at night) was also mentioned in preliminary discussions, with the relatives experiencing the greatest barrier to participating as coresearchers. This was one of the key reasons for our inability to recruit any relatives for the DECIDE-SR project. Consequently, we learned that it is crucial to be able to offer appropriate support services, which could include, for example, the organization of workshops/meetings in facilities that can provide nursing care or home care for the time of involvement.

With respect to the inclusiveness of different perspectives from healthcare professionals, the recruitment of practice partners was successful. In particular, the agreement with superiors that employees could take part in workshops/meetings during their working hours was an important supporting factor. Finally, we were unable to attract coresearchers with a migration background. Their perspectives seem to be essential for addressing health-related themes with comprehensive inclusiveness. However, we learned that the development of suitable strategies for involving people with a migration background is crucial for this purpose and needs to be the focus of a separate project with its own resources. To this end, partnerships with diverse public institutions, the development of a diverse and constant coresearcher group, and an increasing diversity of professional researchers could be important. This could help promote the consistency of the active involvement of coresearchers with a migrant background in future projects.

Implications for further research with active public involvement

In our DECIDE-SR project, we, as a group of coresearchers and professional researchers, developed, tested, and reflected on a framework to actively involve and engage people living with dementia, individuals from their social networks, and healthcare professionals in conducting an SR. Furthermore, we planned and partially conducted a SR with the research question"What is the effect of hospital treatment provided in one's own living place on people living with dementia?"We found that the close cooperation and perspectives of the coresearchers had a significant effect on the planning and possible performance of the SR. Additionally, the coresearchers had a great interest in and desire to actively participate in all steps of the review. The framework and workflow, as well as the lessons learned, are now available and offer other researchers the opportunity to conduct SRs with, for example, people living with dementia and gain initial experience.

Compared with previous experiences and recommendations and principles for the active involvement of heterogeneous groups of coresearchers in research, which also include people living with dementia [11, 24, 34–36], it is clear that many aspects are also important when conducting participatory systematic reviews. For example, building relationships based on mutual trust and respect and the perception of having a significant influence on the research were important for the success of our project. Furthermore, our experience has shown that the attitudes of professional researchers are crucial and that a shift to a coresearcher-centered approach seems important. Particularly with respect to the active involvement of people with dementia in research, current principles often appear to be too general and to reinforce a certain stereotype of the person living with dementia (e.g., memory loss, lack of capacity, or loss of autonomy) [34]. Our framework for individual participation, which is based on preferences, interests and abilities, could pave the way for coresearcher-centered research for participatory systematic reviews, in contrast to the more professional research-centered approach, which is characterized by cherry-picking when coresearchers are involved, when it benefits professional researchers, as described in the Cochrane "Consumer" Network's brief guide [4]. This is because a person living with dementia cannot be reduced to a "typical" dementia patient, since dementia has heterogeneous symptoms, and clinical pictures and the importance of the individual person with their personal history must be the starting point for self-determination of the degree of involvement and all supportive interventions [7, 35, 39]. Following this, there can be no one principle for all, it must always be considered individually and weighed to determine whether a supportive intervention helps or stigmatizes an individual [24]. People living with dementia bring skills, in addition to their lived experiences, to research that results, for example, from their current or previous education, occupation, experiences, or leisure activities (e.g., statistical knowledge from working as a math professor). These skills should be considered and can enrich the research project [11, 35].

In view of the implications of the project and the lessons learned, it seems essential that structures and financial framework conditions that actively support this type of research are needed. In times of ever-increasing funding cuts, it is not enough for funding agencies to simply demand the pursuit of an active involvement and engagement approach. Instead, investments must be made in academic and research organizations and researchers to develop a structure that allows participatory research, including training and building networks with coresearchers to intensify and consolidate the active involvement of the public in dementia care research. This seems essential not only for changing how we want to conduct research but also for increasing our understanding of the purpose of participatory research as well as the effort needed to involve and engage the public.

Furthermore, in the context of active participation in research, it seems important to critically scrutinize simple criteria for evaluating research with active involvement (e.g., effectiveness/efficiency). Preferably, the focus should be on the differences in the results that active involvement leads to and the reasons why the public perspective may differ from the scientific perspective. This appears to be particularly important for disciplines such as nursing science or medicine.

Finally, active involvement in research is time-consuming, and collaboration does not end with the 'end of the project'. Rather, the existing relationship with coresearchers should be maintained, e.g., through regular meetings, as coresearchers are people who can be characterized by a certain vulnerability and do not represent a 'classic' working relationship (e.g., becoming part of their social environment). On the other hand, these relationships should be ongoing to maintain the network that has been established and to continue working on topics (e.g., project proposals). It is not yet known how this additional time aspect can be considered in ongoing projects. The same applies to the need to maintain relationships with the coresearchers after the end of the project. This requires additional financial support to establish, for example, personnel support in the form of employees who can manage this contact.

Supplementary Information

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Supplementary Material 1.

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Authors' contributions

MRM and CM wrote the initial draft of the manuscript. ALH, HR, LF, HK, HB, JB, SO, BA and MR revised the manuscript. All the authors approved the final manuscript. MR, MRM, CM, and HR collaboratively coordinated the study and developed the structure of the study.

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Data availability

No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate

Were unnecessary because all the people were actively involved in the DECIDE-SR project and therefore acted as coresearchers. Members of the research team were financially compensated for attending the meetings, or attending the meetings was counted as work time. More details have been published elsewhere [38].

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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