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# Using community engagement with *FRAME*: Framework for reporting adaptations and modifications to evidence-based interventions

Jordana L. Clayton [a,*], Rebecca L. Utz [a], Nancy Aruscavage [b], Sara G. Bybee [b], Sharon E. Bigger [b], Eli Iacob [b], Kara B. Dassel [b]

[a] *College of Social and Behavioral Sciences, University of Utah, Carolyn and Kem Gardner Commons Suite 3725, 260 S Central Campus Dr, Salt Lake City, UT, 84112, USA*
[b] *College of Nursing, University of Utah, 10 South 2000 East, Salt Lake City, UT, 84112, USA*

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ABSTRACT

Community engagement is increasingly considered a key component of intervention development, as it can leverage community members' knowledge, experiences, and insights to create a nuanced intervention which meets the needs, preferences, and realities of the population of interest. Community engagement exists along a spectrum from outreach to the community to partnership with community members and organizations, and all levels of community engagement can benefit from systematic documentation of community feedback and decision-making processes. This paper demonstrates how we utilized the "Framework for Reporting Adaptations and Modifications to Evidence-based Interventions" (FRAME; Wiltsey Stirman et al., 2019) model to track and report adaptations to our dementia end-of-life care planning intervention based on community engagement via a project-specific Community Advisory Board (CAB). Using FRAME, we generated a comprehensive report of the iterative changes made to our pilot intervention, including whether the change was planned, who made the decision to modify the intervention, the nature of the change, its relationship to intervention fidelity, and the reason for the change. This process ensured that we effectively integrated feedback and assistance from our CAB, increased the appropriateness of our intervention for our population of interest, established criteria to monitor intervention fidelity, and prepared our team to run a rigorous clinical trial of the revised intervention. Clinical Trial Registration Number: NCT05909189.

## 1. Introduction

Community engagement is increasingly being recognized as a key component in developing best-practice, evidence-based interventions [1]. Community-engaged research practices exist on a continuum, ranging from community outreach and education, where community members are minimally involved, to community-based participatory research, where community members are involved in every aspect of decision-making and implementation [1,2]. The most basic form of community engagement is outreach, in which the research team develops and implements strategies to reach the population of interest and educates the population about a particular topic. Next is consultation, in which community members give advice about important elements of the intervention. Third is cooperation, in which community members give advice as well as assistance in defined areas such as recruitment, study activities, the creation of study questions, and the interpretation of outcomes. Fourth is collaboration, in which community members partner with the research team in setting the study priorities, creating the study design, implementing the study, and completing analysis, interpretation, and dissemination. Finally there is partnership, in which a strong, bidirectional relationship exists with equal decision-making power over every aspect of the research process, including study design and implementation, power division, and use of resources beyond the extent of a single project [1,2]. This final stage is also known as Community-Based Participatory Research (CBPR).

All levels of community engagement can be beneficial for research teams and communities. Engaging community members in the research process can raise participation and retention rates [3,4], improve the appropriateness of interventions by identifying problems early [5], enhance research design and implementation [6,7], increase community

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* Corresponding author. 380 S 1530 E RM 301, Salt Lake City, UT, 84112, USA.
*E-mail addresses:* jordana.clayton@utah.edu (J.L. Clayton), rebecca.utz@csbs.utah.edu (R.L. Utz), nancy.aruscavage@nurs.utah.edu (N. Aruscavage), sara.bybee@nurs.utah.edu (S.G. Bybee), sharon.bigger@nurs.utah.edu (S.E. Bigger), eli.iacob@nurs.utah.edu (E. Iacob), kara.dassel@nurs.utah.edu (K.B. Dassel).

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education [8], increase the diversity of research participants [4,9], address health disparities [4,10–13], and improve the health outcomes of public health interventions [13]. Lay or professional community members with personal experience and/or expertise with the content area bring unique knowledge and perspectives which can improve research processes and outcomes [4]. Partnering with community members “involves a cyclical, iterative process … where communications between the community partner(s) and the academic researchers are ongoing and bidirectional” [14, p. 124]. Community engagement is especially important for intervention research, whose goal is to create and evaluate programmatic or supportive tools and procedures that can be implemented in clinical and community settings.

Our research team engaged community members throughout every stage of the design and refinement of the LEAD Intervention (Life-Planning in Early Alzheimer’s and Other Dementias; LEAD) [15,16]. Funded by the Alzheimer’s Association [20–685951] and approved by the University of Utah’s Institutional Review Board [00162125], the LEAD Intervention was designed to help community-based individuals who are at risk for, concerned about, or have received a diagnosis of mild cognitive impairment (MCI) or dementia plan for their long-term and end-of-life care. The intervention also prepares their care partner for a possible future role as a surrogate decision-maker. To ensure our intervention was appropriate and accessible for individuals with cognitive impairment or dementia, who may struggle with orientation and navigating the internet [17–19], we created and engaged a Community Advisory Board (CAB; N = 9). We sought feedback at each stage of development and implementation from our CAB to co-create instructions, study questions, and format the online intervention platform. Our CAB also assisted in making recruitment referrals, interpreting participant feedback regarding the acceptability of the intervention, and using participant feedback to make further changes to the intervention in preparation for a larger clinical trial. This situates our CAB within the “cooperation” level of the continuum of community engagement [1,2].

We utilized the Framework for Reporting Adaptations and Modifications to Evidence-based Interventions (FRAME) developed by Wiltsey Stirman, Baumann, and Miller (2019) to track and implement the feedback generated by our CAB [20]. FRAME uses nine questions to aid researchers in reporting adaptations and provides four categories to help describe the reasons for adaptations (see Table 1). The FRAME model has been used to track adaptations in interventions for Hispanic/Latino [21] and Korean American caregivers [22], a cancer symptom management intervention [23], and an online intervention for sexual and gender minorities with dementia [24]. This model was appealing to our team as a systematic and organized approach to documenting CAB feedback and consequent changes in the intervention design.

This paper provides a case study of how our research team cooperated with a CAB to create an intervention reflecting the community’s needs and values. Our systematic process embraces the importance of community engagement in the design, development, modification, and testing of behavioral interventions [25].

## 2. Methods

Our goal was to recruit a mix of dementia professionals, care partners, and persons with cognitive impairment to join our CAB. We used convenience sampling, relying mostly on our team’s personal and professional connections, to recruit a CAB for this project. After recruitment, our team met with the CAB quarterly over Zoom© video conferencing throughout the intervention development period, where they reviewed the intervention’s design, purpose, structure, and content. We continued to meet with them during the implementation period, while our team conducted a pilot study of the intervention. In accordance with best practices for honoring the valuable time and expertise of our CAB [26–29], we compensated each member $250 per year for their participation. Each CAB member participated for five years on average.

**Table 1**
The Nine Questions to Report Adaptations and Four Reasons for Modifying the Intervention within the FRAME model.

| Framework for Reporting Adaptations and Modifications to Evidence-based Interventions | | |
| --- | --- | --- |
| *Nine Questions to Report Adaptations* | | |
| Number | Question | Examples[a] |
| 1 | When did the modification occur? | Pre-implementation, implementation, scale-up |
| 2 | Were the adaptations planned? | Yes/no |
| 3 | Who participated in the decision to modify the intervention? | The research team, funders, community members, clinicians/providers |
| 4 | What was modified? | Intervention content, method of intervention delivery, provider training, method of data collection |
| 5 | At what level of delivery was the modification made? | Individual participant, clinic level, specific cohort of individuals |
| 6 | What is the nature of the modification? | Tailoring materials for the subject population, removing elements, adding elements, reordering elements, translation services |
| 7 | What is the relationship between modification and fidelity? | Core elements of the intervention are maintained/fidelity is maintained, or not |
| 8 | What was the goal of the modification? | Increase reach, increase retentions, improve feasibility, address cultural factors, reduce cost, increase satisfaction |
| 9 | What is the reason for the adaptation? | *See below* |
| *Four Reasons for Modifying the Intervention* | | |
| Number | Question | Examples |
| 1 | Sociopolitical | Existing laws and policies, political climate, social norms, funding allocation |
| 2 | Organization/Setting | Time constraints, service structure, location, regulatory compliance, billing constraints, available resources |
| 3 | Provider | Race, ethnicity, gender and sexual identity, first/spoken languages, training and skills, clinical judgment |
| 4 | Recipient | Race, ethnicity, gender and sexual identity, access to resources, cognitive capacity, literacy, first/spoken languages, legal status, comorbidity, crisis or emergent circumstances, motivation and readiness |

[a] Examples are taken from the FRAME diagram presented by Wiltsey Stirman, Baumann and Miller [20]. The table does not reproduce all examples provided by the authors, but are included to demonstrate their intended method of answering each question.

Our CAB was tasked primarily with providing feedback on the intervention’s appropriateness and usability during the initial beta-testing of the web-based platform, specifically regarding the navigation, personalization, and content of the three intervention modules. They also were asked to provide input to the research team about the baseline assessment and three follow-up surveys to be completed across the 36 week study period.

In addition to their feedback during the pre-implementation stage, our CAB also provided input on the pilot study results. They provided ideas for intervention improvements and modifications after reviewing suggestions and critiques made by the pilot study participants (N = 96). Participants were comprised of dyads: one individual concerned about, at risk, or recently diagnosed with dementia or MCI, and their current or future care partner. Dyads were recruited through convenience sampling, snowball sampling, and two national research registries: ResearchMatch© [30] and TrialMatch™ [31]. Inclusion and exclusion criteria can be found in Table 2.

**Table 2**
Pilot study participant eligibility criteria.

| |
|---|
| *Patient Eligibility Criteria:* |
| The patient was still able to function independently but is aware of having memory lapses, such as forgetting words and locations of everyday objects, according to the Alzheimer's Association 10 Warning Signs *OR* The patient is a person at-risk or concerned about Alzheimer's or another dementia *OR* The patient has a diagnosis of Alzheimer's or another dementia |
| The patient is 50+ years old |
| *Care Partner Eligibility Criteria:* |
| The care partner is the spouse, long-term partner, or adult child of the patient |
| The care partner is 18+ years old |

During the pilot study of the LEAD Intervention, participants used a five-point Likert scale (from 1 = Strongly Disagree to 5 = Strongly Agree) to rate their agreement with the following statements after each intervention module: 1) The activities were clear, 2) The activities made sense, and 3) The activities were helpful. Participants were also asked to provide additional comments about the activity using an open-text box. Evaluation was completed immediately after the module so participants with cognitive impairment could effectively relay their experiences.

## 3. Results

Our nine member CAB consisted of individuals with personal or professional experience with dementia and dementia caregiving: one licensed clinical social worker specialized in dementia, one staff member from the Utah Chapter of the Alzheimer's Association, one former care partner of an individual with dementia, and two care partner/care receiver dyads. The following summary of our results can serve as a case study on how to use FRAME to thoroughly understand each adaptation made before, during, and after an intervention. Our results are organized in three phases: pre-implementation, implementation, and post-implementation. Examples of intervention adaptations we made and how the CAB was involved in those adaptations are presented in Table 3. The complete list of intervention adaptations can be found in the supplementary material.

### 3.1. *Pre-implementation: adapting the paper-based LEAD guide to a web app*

During pre-implementation, our study team collaborated with University of Utah IT (Information Technology) to determine the optimal software platform for a web-based intervention, and with our CAB to design a website that ensured accessibility for individuals with dementia. We co-developed the educational materials and scripts for the voice-overs and video tutorials with the CAB. Their recommendations fell into three categories: 1) adaptations to the content and intervention platform, 2) adaptations to communication and intervention delivery, and 3) adaptations to intervention evaluation (see Table 3 for examples).

### 3.2. *Adaptations during implementation*

During the early phase of study implementation, study participants noticed design features and word choices that negatively impacted their experiences. To rectify these, our team corrected errors, altered the formatting, and increased the personalization of emails and study surveys through piped text. We also extended hyperlink expiration dates to give more flexibility to participants who needed additional time to complete all elements and to prevent difficulties in sharing new survey links. Lastly, we improved the navigation of the study surveys to allow participants to review instructions as often as they wished (see Table 3 for examples).

### 3.3. *Post-intervention adaptations to the LEAD guide*

Pilot study participants provided feedback on the intervention's foundational component, the LEAD Guide. We brought that feedback to our CAB to discuss the critiques and potential solutions. Utilizing both a Qualtrics© [32] survey on wording and ordering preferences and two Zoom© meetings, we made a series of iterative changes to the content of the LEAD Guide. These changes included reordering sections, adding new elements, and making structural changes to increase question clarity. The revised version of the LEAD Guide is available to the public and is being used in our current and ongoing clinical trial; both versions can be found within the supplementary material.

We also engaged our CAB to evaluate participants' feedback about the structure of the intervention and to improve it for our clinical trial. The updates that we decided on with our CAB included changes to the timing of activities, the style of informational videos, the format of the web platform, and the process for screening participants (see Table 3 for examples).

### 3.4. *Strengths and limitations*

A strength of combining FRAME with community-engaged research was that the majority (n = 8, 88.88 %) of the CAB members wanted to stay involved in the project as we moved from the pilot phase to the clinical trial phase. This high retention rate over multiple projects indicates that our CAB was satisfied with their participation. Unfortunately, our method was limited by the demographic homogeneity of our CAB, who were fairly similar in terms of educational level, race, and ethnicity. A more diverse CAB may have provided more complex feedback to inform intervention development.

## 4. Discussion

Using a structured conceptual framework like FRAME allowed us to document the goals, processes, and outcomes of how our research team collected and used input from a CAB. Combining community engagement and the FRAME model helped us to develop and pilot-test an intervention to support families plan for their future health care after receiving a diagnosis of dementia. FRAME served three primary functions for our research team: first, systematically monitoring feedback streamlined the process of intervention adaptation. Second, rigorous documentation helped monitor intervention fidelity, even through multiple rounds of development and adaptation. Finally, the resulting intervention was better tailored to the community by incorporating their feedback, similar to other interventions that use community engagement [4,26].

Emphasizing community engagement during intervention development and testing has been called for by other researchers [25] and is well aligned with the NIH stage model of intervention development and testing [34]. Community engagement is particularly critical in Stages 1A (creation/development) and 1B (pilot testing) of intervention development, when research teams design an intervention's core elements. Using the FRAME model to guide and document our activities with our CAB helped prepare our early-stage intervention for administration and evaluation in a larger clinical trial (funded by the National Institute on Aging [R01 AG069033]).

While CBPR is the gold standard of community engagement, it requires a high level of commitment from and training for community partners. Finding community partners both willing and able to

**Table 3**
Intervention adaptations tracked with FRAME.

| What Was Modified | Process of Modification | Goal/Reason For Modification |
|---|---|---|
| *Pre-Implementation* | | |
| Input the content of the paper-based intervention into the web-based platform, Qualtrics© [32] | *Planned:* Yes<br>*Who:* Research team, University of Utah IT<br>*Level:* Intervention platform<br>*Nature:* Digitalizing the intervention<br>*Fidelity:* Maintained as purpose is unchanged | *Goal:* Allow intervention to be tracked by study team without being "in person." Allow national access to intervention and increased adjustments for cognitive capacity (font size, color contrast)<br>*Reason:* Provider, Recipients |
| Inserting back arrows for participants to review and revise their responses | *Planned:* No<br>*Who:* Research team<br>*Level:* Intervention platform<br>*Nature:* Adding elements<br>*Fidelity:* Maintained as purpose is unchanged | *Goal:* Allow recipients more flexibility in changing their responses<br>*Reason:* Recipients |
| Shortening instructional videos | *Planned:* No<br>*Who:* Research team<br>*Level:* Content<br>*Nature:* Shortening and condensing elements<br>*Fidelity:* Maintained as purpose is unchanged | *Goal:* Shortening videos improves comprehension and ability to pay attention for individuals with MCI or dementia<br>*Reason:* Recipients |
| Including graphics in instructional videos as well as text | *Planned:* No<br>*Who:* Research team<br>*Level:* Content<br>*Nature:* Adding elements<br>*Fidelity:* Maintained as purpose is unchanged | *Goal:* Including graphics improves comprehension for individuals with MCI or dementia<br>*Reason:* Recipients |
| *Implementation* | | |
| Included piped text with the participant's name into emails and survey questions | *Planned:* No<br>*Who:* Research team<br>*Level:* Intervention delivery, content<br>*Nature:* Adding elements<br>*Fidelity:* Maintained as purpose is unchanged | *Goal:* Make the emails and content more personal to the participants<br>*Reason:* Recipients |
| Changed survey expiry date from one week to one month | *Planned:* No<br>*Who:* Research team<br>*Level:* Intervention delivery<br>*Nature:* Changing elements<br>*Fidelity:* Maintained as purpose is unchanged | *Goal:* Reduce workload for study team in generating a new link and sending it to participants manually<br>*Reason:* Provider, Recipients |
| Reformat hyperlinks to open within a new tab | *Planned:* No<br>*Who:* Research team<br>*Level:* Intervention delivery<br>*Nature:* Changing elements<br>*Fidelity:* Maintained as purpose is unchanged | *Recipients:* Reduce confusion for participants with MCI and dementia when links opened in a new window<br>*Reason:* Recipients |
| Reformat Qualtrics© [32] survey flow and branch logic to allow participants to rewatch an activity's instructional video | *Planned:* No<br>*Who:* Research team<br>*Level:* Intervention platform<br>*Nature:* Adding elements<br>*Fidelity:* Maintained as purpose is unchanged | *Goal:* Improve accessibility for participants with MCI and dementia who struggled to remember task instructions<br>*Reason:* Recipients |
| *Post-Implementation to Prepare for Clinical Trial* | | |
| Updated structure of the LEAD Guide end-of-life preference questions into two health scenarios: current state of health, and a hypothetical future state of severe dementia | *Planned:* No<br>*Who:* Research team<br>*Level:* Intervention content<br>*Nature:* Rearranging elements<br>*Fidelity:* Maintained as purpose is unchanged | *Goal:* Reduce confusion from "If-then" answer style in original document<br>*Reason:* Recipients |
| Shortened intervention timeline from 36 weeks to 20 weeks, including reducing the time between intervention activities from three weeks to one week | *Planned:* No<br>*Who:* Research team<br>*Level:* Length of intervention<br>*Nature:* Shortening time between elements<br>*Fidelity:* Maintained, as the core intervention is the same | *Goal:* Improve retention of previous activities by participants with cognitive impairment<br>*Reason:* Recipients |
| Switched data collection tool from Qualtrics© [32] to REDCap© [33] | *Planned:* No<br>*Who:* Research team<br>*Level:* Platform for study surveys<br>*Nature:* Replacing platform | *Goal:* Reduce study team software difficulties using Qualtrics© [32]; select a data management software designed for longitudinal data<br>*Reason:* Provider |

(*continued on next page*)

**Table 3** (*continued*)

| What Was Modified | Process of Modification | Goal/Reason For Modification |
|---|---|---|
| | *Fidelity:* Maintained, as this adaptation does not alter the intervention | |
| Added a screener survey prior to baseline | *Planned:* No<br>*Who:* Research team<br>*Level:* Screening, consent, and onboarding<br>*Nature:* Separating elements<br>*Fidelity:* Maintained, as this adaptation does not alter the intervention | *Goal:* Reduce number of individuals who screened incorrectly and were enrolled but ineligible<br>*Reason:* Provider |

participate at that level can be challenging or impossible, and research teams also face constraints in financial and time resources to recruit such community partners. Multiple of our CAB members were individuals with dementia and their care partners who may have had difficulty in balancing needed rest, medical care, and caregiving responsibilities while also providing the time commitment necessary to participate in decision-making for every element of the design, implementation, analysis, and dissemination of the intervention. One CAB member with dementia was diagnosed with cancer during the course of the study and had to stop participating during the course of treatment. Other CAB members had limited time to offer outside of their professional and personal commitments. Therefore, while community participation at the level of CBPR would have been ideal, engaging participants at the cooperation level on the spectrum of community engagement balanced receiving extremely valuable assistance and advice with making participation as accessible as possible. We encourage other researchers to engage community partners at the highest level that is feasible for researchers and the community.

Researchers and community partners may face challenges as they begin working together; CAB members may face particular difficulty with research terminology and understanding the research process [4,7,35]. We assisted our CAB by starting each meeting with a brief update in easy-to-understand language about the research process, such as explaining the IRB application and approval process and recruitment protocols. We also encouraged them to ask questions about the research process. We often had to remind our CAB that research timelines are often slower than what non-researchers expect, and we provided education on why some of their ideas or suggestions could not be implemented because of the need to honor all human research subjects' confidentiality and informed consent. We found that our CAB members were very curious and receptive to these instructional moments about research methods and research process. Broadly, research teams may need to adjust their language to accommodate the specific needs of their community partners; in our case, we needed to adjust our conversations to recognize the preferences and capabilities of individuals with dementia [36]. Becoming aware of these language differences during the pre-implementation period improved our intervention as well by allowing us to create research instruments and intervention language that were tailored to the needs and preferences of the target population.

Employing community engagement practices can substantially raise the financial and time costs of research. Best practices suggest that community advisors be paid in a way that fairly compensates them for their time and expertise [26–29]; we paid ours $250 per year with most of them working about five years. For our clinical trial, this was increased to $500 a year to account for inflation and the increased expertise our community partners had from their time and experience with our team. Community engagement also adds time to the research process. The research team needs to account for the time it will take to recruit and train CAB members to the specific research team and project, present ideas, seek feedback, and then incorporate feedback from the CAB. This process of gathering community participation and feedback can lead to unexpected adaptations throughout intervention design and implementation; one community-engaged researcher recommends doubling the initial budget allotted for community partners to anticipate these unplanned project needs [5]. However, early-phase adaptations made prior to implementation may end up being more cost-effective than late-stage adaptations [37], and community engagement can help identify necessary adaptations earlier in the research process. Future research should provide empirical data on the costs and time associated with community-engaged research practices and develop guidelines on budgetary planning related to community engagement. To this end, one recent study documented the time and costs associated with using community engagement compared to more traditional research practices; it reported that while community-engaged recruitment practices lead to higher diversity in the sample, it was one of the costliest recruitment methods tested [9].

In considering the additional time and funding necessary to engage community members in the development and pilot-testing of the LEAD Intervention, we believe the investment in community engagement was worth the investment. Having our CAB complete beta-testing of the intervention added approximately two months of additional time to the development phase of the intervention, as the research team had to make iterative changes based on feedback from the CAB. However, without the assistance of our CAB, the problems that they identified within our intervention would have been faced by participants instead. This was particularly important for improving the accessibility of the intervention for individuals with cognitive impairment or early stage dementia.

Our CAB also found participation in our research to be personally satisfying. In particular, the individuals with dementia and their care partners, and the former care partner of an individual with dementia, often express their gratitude for being able to work on a project that would have immensely helped them if they had access to it earlier in their dementia diagnosis trajectory. They strongly believe in the utility of the LEAD Guide and want to make it accessible to as many people as possible. This is somewhat different from CABs that are comprised more entirely of professionals within the community who find that participation aids in their professional networking and practice [35].

To aid other research teams in combining FRAME with community engagement, we have created a template for using the FRAME model to track intervention adaptations (see supplementary material). The template includes three "when" sections for each stage of intervention development: pre-implementation, implementation, and post-implementation. All three phases are associated with a pilot study, and should ideally be completed prior to a larger clinical or community-based trial of intervention efficacy and effectiveness. The template provides space for each of the nine questions in FRAME and areas to track the reasons behind each adaptation, and is designed to be flexible enough to record community feedback and decision-making across the spectrum of community-engaged research, from outreach to CBPR.

If the FRAME template is used to track feedback and decisions from the beginning of the community engagement and research design process, even in an imperfect way, it does not add a considerable burden of time or effort. Instead, it can provide a structured way to consistently track the many detailed updates to an intervention's protocol. We recommend bringing the template to team meetings or creating a schedule on which to update it. We believe this can distribute the time and effort of tracking iterative changes over the course of the design process, making it much simpler to report on adaptations and the design process at the end of the intervention. It can also increase the completeness of reporting, so that not only the changes made but the reasons for those changes can be understood.

We believe using FRAME to document the influential role of community-engaged research has the potential to create interventions that serve the needs of the community of interest, since the community's insights, values, expertise, and experience shape the development and refinement of interventions at every stage. All levels of community engagement can bring immense benefit to both research teams and to community partners. Centering the community's needs and values has the potential to expedite the design, implementation, dissemination, and translation of an intervention, leading to better outcomes for both communities and research teams.

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## CRediT authorship contribution statement

**Jordana L. Clayton:** Writing – review & editing, Writing – original draft, Formal analysis, Conceptualization. **Rebecca L. Utz:** Writing – review & editing, Methodology, Conceptualization. **Nancy Aruscavage:** Writing – review & editing, Writing – original draft, Project administration. **Sara G. Bybee:** Writing – review & editing, Methodology. **Sharon E. Bigger:** Writing – review & editing. **Eli Iacob:** Writing – review & editing, Data curation. **Kara B. Dassel:** Writing – review & editing, Supervision, Methodology, Funding acquisition, Conceptualization.

## Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

## Glossary

**Adaptation:** "Adaptation refers to the modifications of the intervention itself or the necessary alterations in the supporting infrastructure" [38].

**Community Advisory Board:** "Community advisory boards (CABs) often serve as a source of leadership in the partnerships of community-based participatory research (CBPR) and provide structure to guide the partnership's activities. CAB composition typically reflects the community of interest; its members may share a common interest, identity, illness experience, history, language, or culture (1). CABs provide an infrastructure for community members to voice concerns and priorities that otherwise might not enter into the researchers' agenda, and advise about suitable research processes that are respectful of and acceptable to the community" [26].

**Community-Engaged Research:** "Community engagement and community-engaged research methods (CEM) involve bringing studied communities into a project or research process as intentional contributors, participants, and/or reviewers. Partnering with community members and people with lived experience during research, policymaking, or practice presents opportunities to enrich the work, incorporate perspectives that are often excluded from decisionmaking, and advance equity across disciplines and professions. Participatory methods center the voices and experiences of community members in a project's process and aim to balance power dynamics between researchers and the community. This can lead to processes and outcomes that are more ethical, effective, and sustainable" [27].

**Community-Based Participatory Research (CBPR):** "CBPR is a collaborative research approach that equitably involves community members, researchers, and other stakeholders in the research process and recognizes the unique strengths that each bring. The aim of CBPR is to combine knowledge and action to create positive and lasting social change" [39].

**Dementia:** "Dementia is the loss of cognitive functioning — thinking, remembering, and reasoning — to such an extent that it interferes with a person's daily life and activities. Some people with dementia cannot control their emotions, and their personalities may change. Dementia ranges in severity from the mildest stage, when it is just beginning to affect a person's functioning, to the most severe stage, when the person must depend completely on others for basic activities of daily living, such as feeding oneself" [40].

**Dissemination:** "Dissemination is the targeted distribution of information and intervention materials to a specific public health or clinical practice audience" [38].

**Fidelity:** "Fidelity refers to 'the adherence of actual treatment delivery to the protocol originally developed'" [38].

**Intervention:** "Intervention is an intentional action (singular or constellation) designed for an individual, a community, or a region that alters a behavior, reduces risk or improves outcome. Interventions can be a medical or behavioral therapy, modification to the natural or built environment" [38].

**Implementation:** "Implementation is the use of strategies ot adopt and integrate evidence-based health interventions and change practice patterns" [38].

**Mild Cognitive Impairment:** "Mild cognitive impairment (MCI) is a condition in which people have more memory or thinking problems than other people their age. The symptoms of MCI are not as severe as those of Alzheimer's disease or a related dementia. People with MCI can usually take care of themselves and carry out their normal daily activities" [41].

**Pilot Study:** "A pilot study asks whether something can be done, should the researchers proceed with it, and if so, how. … it is conducted on a smaller scale than the main or full-scale study … in order to assess the safety of treatment or interventions and recruitment potentials, examine the randomization and blinding process, increase the researchers' experience with the study methods or medicine and interventions, and provide estimates for sample size calculation" [42].

**Surrogate Decision-Maker:** "If an individual is unable to make decisions about personal health care, some other individual can be authorized to provide direction. Such a person is called the surrogate decision maker" [43].

## Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.conctc.2024.101398.

## Data availability

De-identified feedback from our community partners is available upon request.

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