

**Helping Older Adults Promote Emotional Well-being (HOPE): A Co-designed Intervention  
to Reduce Internalized Stigma of Seeking Mental Health Services**

by  
Jagpreet Kaur

A thesis submitted to the Faculty of Graduate and Postdoctoral Studies of  
THE UNIVERSITY OF MANITOBA  
In partial fulfillment of the requirements of the degree of  
MASTER OF ARTS

Department of Psychology  
University of Manitoba  
Winnipeg, Manitoba

Copyright © 2026 by Jagpreet Kaur

### Abstract

Mental health problems are common among older adults, yet this age group is the least likely to seek mental health services. Internalized stigma of seeking help, defined as the internalization of negative societal beliefs about seeking mental health services, is a key barrier. While various interventions exist to reduce internalized stigma among younger populations, only two have been specifically designed for older adults, both of which were developed before the new zeitgeist of involving individuals with lived experience in the intervention design process. Following this new zeitgeist, we used a community-based participatory research (CBPR) framework and co-design methods to guide the development of an anti-stigma intervention for older adults. Eleven team members, including four academic researchers and clinicians, five older adult community team members, and two video design experts, leveraged their expertise to collaboratively develop this brief video intervention over the course of eight monthly co-design meetings. These meetings were audio-recorded and transcribed verbatim. Resulting transcripts, field notes, and reflexive journaling helped document the shared decision-making process and how the principles of authentic partnership were enacted. Additionally, team members completed the patient engagement evaluation tool (PEET-6) anonymously at the end of each meeting, with results shared at the start of subsequent meetings to monitor and evaluate the ongoing quality of the collaborative partnership. Finally, we used structured co-design reporting guidelines to document our co-design process across three stages: planning, conducting, and evaluation.

*Keywords: internalized stigma, older adults, intervention development, CBPR, co-design*

### **Acknowledgements**

First and foremost, I would like to acknowledge and extend my gratitude towards this land of Indigenous peoples for providing me with a place to live, air to breathe, water to drink, and a place to attain higher education, which has given me the opportunity to dedicate my life to serving humanity through research and clinical work.

Next, I would like to extend my gratitude to my advisor and committee members for supporting me throughout this process and investing their valuable time in my growth. I do not have enough words to describe how grateful I am to my advisor for supporting me throughout this process, and for showing faith and trust in my abilities to undertake this project.

I am immensely grateful to our older adult team members for sharing their amazing stories and perspectives for this project. I would also like to thank our video design experts for their creativity and support in helping bring this project to life. Further, I would like to thank our amazing research assistant, who stayed on top of everything to help me coordinate this process.

I would also like to thank my mom and brothers who prayed every day for my success, and supported me whenever I felt anxious and overwhelmed. I would also like to thank my dearest friends and colleagues to support me throughout this journey. I am forever grateful to all of you.

Finally, I gratefully acknowledge the financial support provided by the Social Sciences and Humanities Research Council of Canada (SSHRC) and Tripwire Media Group to support this research.

**Table of Contents**

|                                                                |     |
|----------------------------------------------------------------|-----|
| Abstract .....                                                 | ii  |
| Acknowledgements .....                                         | iii |
| List of Tables .....                                           | vi  |
| Introduction .....                                             | 1   |
| The Mental Health Service Gap .....                            | 1   |
| Limitations of Stigma Reduction Interventions .....            | 2   |
| Anti-Stigma Intervention Co-Design .....                       | 6   |
| Planning .....                                                 | 6   |
| Framing of the study aims. ....                                | 6   |
| Recruitment. ....                                              | 7   |
| Conducting .....                                               | 9   |
| Structure of co-design meetings. ....                          | 9   |
| Manifesting meaningful collaboration and shared ownership..... | 10  |
| Procedural components and methods .....                        | 12  |
| Evaluation.....                                                | 19  |
| Process evaluation. ....                                       | 19  |
| Outcome.....                                                   | 22  |
| Critical Reflection & Discussion .....                         | 23  |
| References .....                                               | 32  |

Appendix..... 49

Meeting Agendas..... 49

**List of Tables****Table 1**

*Revised Checklist for Reporting Intervention Co-Design (Leask et al., 2019) ..... 42*

**Table 2**

*Overview of Co-Design Meetings ..... 43*

**Table 3**

*PEET-6 Scores for All Meetings, Reported as Mean (Range) ..... 44*

**Table 4**

*Attendance Record: Number of Co-Design Team Members Present at Each Meeting ..... 45*

**Table 5**

*Key Recommendations for Facilitating Co-Design Processes.....46*

## **Introduction**

Many older adults experience stress due to significant life changes such as retirement, the loss of loved ones, and physical health challenges (World Health Organization [WHO], 2023). While most successfully adapt to these major life events, a significant minority of older individuals experience clinically significant emotional difficulties. According to the WHO, approximately 14% of older adults currently live with mental disorders (2023). Similarly, in a nationally representative US sample about 11% of older adults had an anxiety disorder, 7% had a mood disorder, and approximately 14% had a personality disorder in the past year (Reynolds et al., 2015). Furthermore, nearly one in five older adults experience subthreshold depression in the past year (Zhao et al., 2024).

### **The Mental Health Service Gap**

Despite the high prevalence of mental health challenges among older adults, research indicates that this age group is the least likely to seek mental health services when needed (Adams et al., 2023; Byers et al., 2012; Mackenzie et al., 2010; Mackenzie & Pankratz, 2025; Reynolds et al., 2020). Older adults with mood and anxiety disorders are approximately half as likely to seek professional help compared to middle-aged adults (Mackenzie et al., 2012), and in 2017, only 10.5% older Canadians sought professional mental health services for mood and anxiety disorders (Tam, 2020). Not seeking help in a timely manner can lead to negative outcomes for individuals and exacerbate mental health symptoms over time (Speerforck & Schomerus, 2020). Therefore, it is essential to understand the barriers to help-seeking among older adults and to implement strategies to encourage them to seek help.

A large body of research has examined why older adults are less likely to access mental health services than their younger counterparts (Elshiakh et al., 2023; Lavingia et al., 2020;

Mackenzie & Pankratz, 2025). These barriers can be broadly categorized into social, structural and psychological categories (Mackenzie et al., 2022). Social barriers to mental health service utilization include public stigma and societal beliefs that view mental disorders as a normal part of aging (Lavingia et al., 2020; Pescosolido & Olafsdottir, 2013; Wuthrich & Frei, 2015).

Structural barriers encompass factors such as cost, transportation, and the lack of geriatric healthcare providers (Elshaikh et al., 2023; Lavingia et al., 2020). Psychological barriers include a lack of perceived need, negative attitudes towards mental health care, personality characteristics, lack of mental health literacy, and internalized stigma of seeking help (Elshaikh et al., 2023; Mackenzie & Pankratz, 2025). While societal and structural barriers operate externally and require changes at systemic levels, psychological barriers operate internally and can therefore be targeted using psychological interventions (Pepin et al., 2009).

Internalized stigma of seeking help, defined as the internalization of public stigma of seeking help, is a key intrinsic psychological barrier contributing to negative help-seeking attitudes and intentions among older adults (Elshaikh et al., 2023; Mackenzie & Pankratz, 2025). Studies have also found this type of stigma to be a better predictor of help seeking behaviors than the internalized stigma of having an illness (Vogel et al., 2024). Therefore, reducing internalized stigma of seeking help is a strong candidate for improving help seeking among older adults.

### **Limitations of Stigma Reduction Interventions**

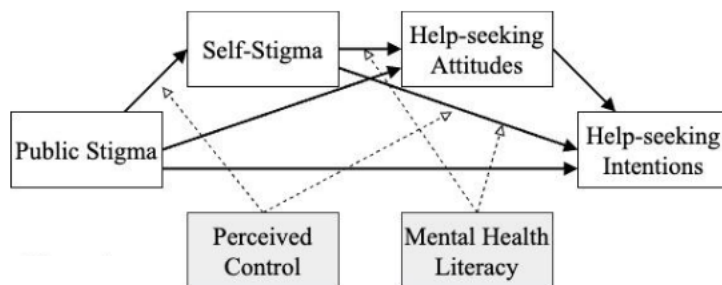
Several anti-stigma interventions have been designed to improve help-seeking attitudes, intentions, and behaviors among individuals with mental disorders to promote both formal and informal help-seeking (Thornicroft et al., 2016; Xu et al., 2018). Many of these interventions have targeted both disorder-specific stigma and stigma on a broader scale by involving families, primary care professionals, and communities. While the outcomes varied, many of these

interventions resulted in small but significant changes in help-seeking attitudes and intentions. However, this large body of stigma research is limited in three key ways that the current study will address: (1) very little stigma intervention research has focused on older adults, (2) the research that does exist with older adults has not been informed by theory or research, and (3) this research has rarely incorporated participatory research methods.

A recent review found only two anti-stigma interventions developed for older adults (Mackenzie et al., 2022). Further, these interventions didn't specifically address internalized stigma of seeking help, and instead focused on stigma of having a mental illness and treatment adherence for depression (Conner et al, 2018; Sirey et al., 2005; 2020). In contrast, many interventions have been developed to target internalized stigma of seeking help for adolescents and adults (Thorncroft et al., 2016; Xu et al., 2018). This large body of research may not be applicable for older adults because age can affect which types of stigma interventions are most effective (Corrigan et al., 2012; Wong et al., 2018). For example, contact-based interventions are more effective for adults, while educational interventions are more effective for adolescents (Corrigan et al., 2012). There is therefore a need to develop anti-stigma interventions tailored to meet the specific needs of different age groups, rather than applying a one-size-fits-all approach.

The second way in which stigma intervention research for older adults has been limited is that existing interventions have not been guided by theory, such as Vogel and colleagues' (2007) internalized stigma model. This model suggests that public stigma of seeking help leads to self-stigma of seeking help, which in turn fosters negative attitudes towards seeking help, resulting in reduced intentions to seek help. Mackenzie and colleagues (2019) found that although older adults generally report lower levels of self and public stigma of seeking help than younger adults, they were more likely to internalize public stigma when they do experience it. Thus, the results

supported Vogel and colleagues' theoretical model of internalized stigma as applicable to older adults. Subsequent research identified two factors that moderate this theoretical mediation model for older individuals: perceived control (PC; Murphy et al., 2024) and mental health literacy (MHL; Mackenzie et al., 2025). PC refers to an individual's subjective assessment of their ability to manage life challenges and influence outcomes (Rothbaum et al., 1982). MHL refers to the knowledge and beliefs about various mental health disorders along with the information about how to seek help for these disorders (Jorm, 2000). This suggests that older adults with lower levels of perceived control and mental health literacy are more likely to internalize public stigma as self-stigma, which in turn has negative effects on help-seeking attitudes and intentions. The pathways through which these moderators affect the internalized stigma model are shown in Figure 1.



*Figure 1. Pathways linking PC and MHL to self-stigma and negative help-seeking attitudes and intentions.*

The third way in which stigma intervention research has been limited is that most existing interventions have been developed without the involvement of end users. Key stigma initiatives such as The Lancet Commission (Thornicroft et al., 2022), and the Public Health Commission of Canada have emphasized the importance of developing anti-stigma interventions by “incorporating theory, lived experience and existing knowledge about ‘what works’” (2020, p. 13). Given this much needed new zeitgeist of involving end-users and relevant stakeholders in

the intervention development (Palmer et al., 2019), we aimed to integrate our research knowledge with older adults' lived experiences and needs to ensure that the developed intervention is both theoretically sound and directly speaks to the needs of older adults.

Thus, the overall research process for developing our anti-stigma intervention was guided by a community-based participatory research (CBPR) framework using co-design methods. We chose CBPR because it complements co-design methods through its inclusive and flexible approach, emphasizing co-learning and equitable collaboration among researchers, end-users, and relevant stakeholders (Collins et al., 2018). It is also becoming an increasingly used framework in developing health interventions (Collins et al., 2018; Wallerstein, 2021). Together, CBPR and co-design methods offer a more collaborative approach that differs from traditional consultation with community advisory boards by actively involving end-users in the decision-making process throughout the intervention development process (Thorburn et al., 2024).

While there is increasing evidence of using various co-design methodologies to develop interventions, concerns persist regarding the transparency of the development process, raising questions about the rigor and quality of the collaborative partnerships between academics and end-users in developing these interventions (Kilfoy et al., 2024; Yau et al., 2024). In other words, was the approach genuinely collaborative, or merely tokenistic? To address this concern, there is a growing demand for more transparent documentation of the co-design process to show how principles of genuine collaboration—such as trust, plurality of knowledge, equitable collaboration, mutual and reciprocal benefit, sustainability, iterative feedback cycles, and shared ownership—were adhered to throughout the process (Collins et al., 2018; Leask et al., 2019; Zogas et al., 2024).

The objective of this study is to transparently document the co-design process used to

develop an anti-stigma intervention for older adults, and to illustrate how the principles of authentic partnership were enacted to produce a theoretically grounded, and user-centered intervention.

### **Anti-Stigma Intervention Co-Design**

We<sup>1</sup> employed co-design reporting guidelines, developed by Leask and colleagues (2019), to guide and document our intervention development process (see Table 1). Accordingly, we present the documentation process in three sections: (1) planning, (2) conducting, and (3) evaluation. Each of these sections has components and checklist items. Of note, we adapted and rearranged checklist items from Leask et al. to enhance the clarity and overall flow of this paper.

#### **Planning**

The initial planning for this study began with co-authors CM and LK preparing a grant application for the Social Sciences and Humanities Research Council (SSHRC). Once the funding for this project was secured, planning involved two key components: Framing of the study aims and recruitment (see Table 1).

**Framing of the study aims.** Using a CBPR framework, our goal was to collaboratively develop a brief video intervention in collaboration with clinical researchers, older adults, and video design experts to reduce internalized stigma of seeking mental health services among community-dwelling older adults. Although CBPR and co-design research proponents recommend involving end-users throughout all stages of the research process, including the inception of the initial idea (Collins et al., 2018; Marrone et al., 2020; Vishwanathan et al., 2004;

---

<sup>1</sup> I am aware that an MA thesis is a solo authored publication. However, given this intervention was co-designed, I didn't find it appropriate to use "I" language, and instead used "we" throughout.

Wallerstein et al., 2017), this is not always possible. Nevertheless, end-users can be meaningfully involved in later stages of the research process, particularly during intervention development (Zogas et al., 2024). Recognizing this possibility, we employed co-design methods to involve older adults and other relevant stakeholders in our intervention development process to ensure it was both relevant and user-centered.

**Recruitment.** Our co-design team consisted of 11 individuals from 3 groups: 4 clinician researchers (CRs), 2 video design experts (VEs), and 5 older adult community members (OAs). The CR group included clinical geropsychologists working in academic ( $n = 3$ ) and clinical ( $n = 1$ ) settings (3 women, 1 man). Two of these research team members (CM & JK) were primarily responsible for recruiting the remaining co-design team members. Following approval of the SSHRC grant for this project, we hired Tripwire Media Group, an award-winning company recognized for excellence in storytelling, and worked with two of their VEs (1 woman, 1 man). Their role was to collaboratively translate the discussions and ideas that emerged during the co-design process into a professionally produced video intervention. Further, we hired a research assistant (JH) to help with team coordination, scheduling meetings, conducting regular team check-ins, and other project-related needs as they arose.

Once the CR and VE groups were established, we started the critical process of recruiting OA team members using purposive sampling. To ensure that these team members represented the target population for this intervention, we aimed to recruit older adults who (1) were aged 60 years and above, (2) experienced mental health challenges, (3) were well-spoken and comfortable sharing their ideas in a group setting, and (4) reported self-stigma of seeking mental health help.

We employed diverse recruitment methods, including distribution of flyers at community

centers and senior organizations, brief presentations at older-adult serving non-profit organizations, and requests for psychologists from our professional networks to share our recruitment poster with their older clients. These recruitment efforts resulted in a small pool of potential participants that JK contacted for a brief 15-20 minute telephone screening interview to assess our inclusion criteria and to ask questions from the 3-item self-stigma of seeking help scale (SSOSH-3; Brenner et al., 2021). For our purposes, we considered an item score of  $\geq 3$  on any SSOSH-3 item to indicate the presence of self-stigma. Participants responded to the SSOSH-3 items based on both their experiences at the time of screening and, retrospectively, when they first accessed mental health services. In addition to using this scale quantitatively, we also used it to facilitate discussion about participants' past experiences of self-stigma of seeking help. This way, both current and past experiences of self-stigma were considered when selecting participants for this study.

We considered all individuals who met the recruitment criteria, and made concerted efforts to ensure a diverse sample in terms of ethnicity and gender. Since most of those who expressed interest were White women, not all could be selected. Recruitment decisions were made to ensure the inclusion of at least one older male adult and one racialized older adult.

Further, while recruiting older adults for this study, the research team discussed the inherent power dynamics in this research approach which could make older adult community team members hesitant to share their ideas. Therefore, to support a more comfortable and inclusive environment, we also recruited two older adults with advocacy experience who were actively engaged in the community. Both individuals brought extensive experience working with and advocating for older adults. One of them had also experienced mental health challenges in the past and reported self-stigma of seeking help. These two older adults did not complete the

telephone screening interview.

This process resulted in five OA team members (4 women, 1 man). These older adults ranged in age from 60 to 73 years, four were White and one was from a racialized group, and they reported a range of mental health experiences, including depression, caregiving burden, grief, adjustment challenges, and severe mental illness. All older adult team members were provided with an honorarium of \$200 for their time and participation, reflecting the principle of mutual and reciprocal benefit; one asked to redirect their honorarium to other aspects of the project.

### **Conducting**

As outlined in Table 1, this section provides an overview of the structure of our co-design meetings, in addition to describing how we manifested collaboration and shared ownership, as well as implemented procedural components and methods.

**Structure of co-design meetings.** Once the co-design team was assembled, we had eight monthly 90-minute co-design meetings between October 2025 and June 2026. See Table 2 for an overview of meeting topics. These meetings provided a structure to co-design the intervention and facilitate meaningful engagement among team members, enabling them to contribute their unique expertise and openly discuss their ideas. Two core research team members (JK & CM) facilitated these meetings which took place in a private room at a community library located centrally in Winnipeg, Canada. The team agreed to continue meeting at this location because it was centrally located, safe, accessible to public transit, with ample parking. Further, meeting format and frequency were determined collaboratively with all team members during the first co-design meeting. Subsequent meetings were scheduled in advance to accommodate the schedules of as many team members as possible.

We recorded and transcribed team meetings using Rev transcription software to maintain an audit trail of key discussions and decisions throughout the development process. Additionally, the research assistant kept field notes during each meeting to capture group dynamics, interactions, and contextual observations. The first author (JK) also maintained a reflexive journal after each meeting to consider potential biases and identify changes that could strengthen the co-design approach in subsequent sessions. We also used Rev to generate summary reports for each meeting, which were reviewed by the first author for accuracy. These summaries helped us track emerging key points of our discussions, and were used to provide an overview of previous meetings, thereby, facilitating member checking.

In between co-design meetings, two CR team members and a research assistant (JK, CM, JH) held additional planning meetings biweekly at the outset of the project and weekly following the first co-design meeting. The purpose of these additional meetings was to reflect on prior meetings, plan upcoming sessions, review field and reflexive notes, and identify changes needed to enhance meaningful collaboration within the team and optimize intervention development (Fix et al., 2024). Two additional meetings were held with the CR and VE team members prior to meetings 5 and 6, so that the research team could comment on video prototypes the video team had developed prior to bringing them to the larger team.

**Manifesting meaningful collaboration and shared ownership.** As shown in Table 1, this section captured different strategies we used to enact the meaningful collaboration and shared ownership.

First and foremost, recognizing trust and relationship-building as central to meaningful collaboration (Baldwin et al., 2018; Collins et al., 2018; Khan et al., 2025; Zogas et al., 2024), we focused on fostering relationships among team members at these meetings. We did this in

numerous ways, such as bringing snacks and coffee to meetings and allowing time for casual conversations beforehand, during breaks, and afterward. These small practices helped build relationships among team members and supported meaningful contributions to the project.

During the first meeting, the importance of equitable participation and shared ownership was emphasized: “Everyone here..... is a partner, we all have our own valuable expertise which we're going to bring to this project, ..... and develop this video in collaboration with each other” (CR). Further, at the beginning of this meeting, the research team provided everyone with a binder and handouts that included the agenda, information about CBPR, and an overview of research on key concepts to establish a common understanding of project’s goals. All these handouts and agenda were typed in an accessible format: Font (Aptos body), size (14-16) to enhance readability. Additionally, to foster a shared sense of purpose and ownership, team members were invited during introductions to reflect on *why the project was important to them* and to describe the expertise they would contribute. During the second meeting, the name of the team (HOPE: **H**elping **O**lder Adults **P**romote **E**motional Well-Being) was chosen collaboratively. Each team member wrote their suggestions for the team name on a flip chart and then placed stickers besides their two top choices. This process reinforced collaboration, shared decision-making and the sense that everyone’s voice matters.

Another way that we emphasized collaboration and shared ownership was to have our research assistant contact older adult team members by phone after each meeting. These check-in calls allowed us to explore how they were feeling during and following the meetings. Importantly, these calls encouraged participants to share their ideas or feelings during the co-design meetings, helping us gather additional feedback to improve future meetings. For instance, at the beginning of the project several older adults expressed concerns with our research assistant

about not feeling they have anything valuable to contribute to this project compared to other team members. In our subsequent meetings, we addressed these concerns by openly discussing and acknowledging that everyone has unique expertise to offer, which is equally valuable to the project. In this way, these between-session check-ins helped build awareness of any concerns that were arising, ensured clear communication, and reinforce the collaborative nature of our project.

A final way in which we shared ownership was to invite the OA and VE team members to be co-authors on any publications and conference presentations related to this project.

**Procedural components and methods.** In this section, we present key procedural components and methods, reflecting checklist items 2.3-2.10 in Table 1. In addition to discussing project goals and team roles, we also highlight key decisions that arose from our collaborative discussions in our meetings, including those related to the video format and other core elements of the intervention, which were informed by both team members' expertise and relevant research evidence. Emphasizing the key components and decisions allowed us to capture various examples demonstrating principles of shared-decision making, upskilling (plurality of knowledge), and the iterative process of development of our video intervention.

Besides discussing principles of equitable participation and shared ownership, the research team began the first team meeting by reviewing the project goals, timelines, and expectations for all team members (checklist item 2.3). Following the principle of valuing different kinds of expertise, researchers would contribute their research and clinical expertise, older adults would share their lived experiences, and the creative team would leverage their creative video production skills. The message in the first meeting was that these combined kinds of expertise would allow us to co-design the intervention in a much more effective way than any

single group could do on their own. Accordingly, team members were asked to provide their thoughts and feedback at each discussion point throughout the development process (checklist item 2.4).

A procedural method we used to keep our team on track and to ensure our discussions remained relevant was to begin each meeting with a flexible agenda that the research team provided and asked for feedback on. These agendas included subtasks related to our overarching goal of making key decisions related to video development. See Appendix A for agendas.

***Video format and content.*** During the first meeting, video design experts presented a 20-minute overview of their creative process, and three different video options for our project. The first option was an animation-only video, the second option combined live video interviews with animation, and the third option featured live audio interviews that would provide voiceovers for an entirely animated video. Team members were encouraged to consider which video format they would like for this project and to discuss their thoughts at the next meeting.

During our second meeting, older adults raised concerns that animation may not be appropriate for our purposes, as older adults may find it “cartoonish”: “There’s a real major association in our age group with animation being somewhat childish” (OA). After a discussion and reassurance by the design team about this concern, all team members collaboratively agreed to option 2, which includes on-camera interviews accompanied by animation, enabling the video designers to use animation to enhance the video interviews, making them more engaging:

I like option two because you have the live interview and the symbols that people are using, the images that they are using would drive the animation so that they'd be absolutely together and that would create the continuity ...in it and allow it to expand. So people's voices would have a graphic like realization. (OA)

This option required us to recruit older adults to appear in the video, as our creative team strongly recommended recruiting real people rather than actors to create a more authentic and impactful video. Our CR team discussed two options, including recruiting older adults who were not part of the project using our social and professional networks, and asking our OA team members if they would be interested in appearing in the video. We presented these options at our team meeting and four of the OA members expressed interest in appearing in the video and sharing their stories. To ensure these team members were making an informed decision, we cautioned them about the implications of appearing in the video and gave them time until the next meeting to think carefully about it. During the following meeting, these team members remained interested and were therefore featured in our video intervention.

Our team then discussed how best to frame the video that would focus on their stories. The OA team members shared their personal experiences with mental health, emphasizing that everyone's journey is different and cannot be accurately captured with diagnostic labels such as anxiety and depression. Team members noted that viewers might not even realize they are experiencing specific kinds of mental disorders, which could reduce its relevance for them:

In my case, I ....didn't recognize that I probably had depression, so I was going through different problems and concerns that I didn't label ....as depression. I'm still not even sure it is, but so if you stick to just depression and anxiety, you might be missing out on some things. (OA)

This discussion led to a decision to focus the video on common and diverse reasons why an older person might experience mental health challenges. Team members felt that this frame, rather than one that uses pathologizing diagnostic language, was important for portraying older adults seeking mental health help as both struggling and as having strengths. This frame also had

the advantage of enhancing relatability, especially among those who may avoid labels or who do not recognize their symptoms as a disorder. Finally, our team agreed to incorporate multiple diverse stories in our video to engage a broader audience.

Following our video design experts' suggestions, we also explored what we want the audience to do after watching our video intervention. We brainstormed various actions to guide our intended audience toward helpful resources. After an open discussion, we agreed that we want the audience to reach out to someone they trust or to mental health resources for help and support. Accordingly, a message of reaching out to someone you trust was included in the video. Concerning mental health resources, CR members emphasized the importance of having well-known and reliable resources, while OAs highlighted the value of directing viewers to somewhere that they can have direct conversations with a person instead of dealing with confusing websites or automated answering systems when contacting mental health resources. Drawing from these suggestions, the CR team identified relevant and stable national resources to feature at the end of the video, including their phone numbers and websites. Specifically, 211 and 988 were included in the video because they are well-known, well-funded, national resources that we hope will contribute to the sustainability of our video intervention.

***Research evidence.*** Throughout our intervention development process, all team members shared different kinds of valued knowledge and skills with one another, with CR members focusing on clinical experience and knowledge regarding research evidence concerning stigma and existing interventions. For example, the first meeting involved a brief discussion about what stigma is, gaps in the research evidence concerning stigma interventions for older adults, and the expected research contributions of this project. The CRs provided handouts with definitions of technical terms in lay language to facilitate understanding of academic concepts, such as

definitions of internalized stigma of seeking help, mental health literacy, and perceived control.

During our third meeting, team members were provided with printed slides and a presentation on Vogel's (2007) theoretical model of internalized stigma of seeking help, as well as its moderators, MHL and PC. This rationale for targeting MHL and PC enabled us to initiate discussions among our older adult team members to explore whether these factors affected their mental health journeys. Additionally, when OAs shared their lived experiences, academics were able to connect these accounts to the themes of PC and MHL, demonstrating how these factors were reflected in different aspects of their stories and could be translated into lived experiences within the final video intervention:

I'm so glad we've been discussing this [example of an adult participant discussing control over her life circumstances] today. So now we want to develop an intervention which targets those perceived control pieces and mental health literacy from the research side of things. We want to develop [an] intervention which strengthens .... perceived control and mental health literacy. (CR)

Additionally, we shared with the team a one-page summary of a systematic review of existing anti-stigma interventions (Makhmud et al., 2022). The purpose was to ensure that the entire team understood the elements of evidence-based interventions, such as emotional tone and relevance, so that they could be incorporated into our intervention. Further, after our second meeting the research team emailed the team links of existing video interventions targeting perceived control and mental health literacy.<sup>2</sup> These videos were also played during our third co-design meeting to help team members visualize how these moderators have been targeted in existing interventions. All research material is available upon request.

---

<sup>2</sup> [https://www.youtube.com/watch?v=7VTijZxdo\\_8](https://www.youtube.com/watch?v=7VTijZxdo_8); <https://www.youtube.com/watch?v=6tBKkJzhGWU>

***Development of storyline.*** Our video design team employs the science of storytelling in their work (Storr, 2020; Suzuki et al., 2018). To prepare the storyline and to get feedback on the direction of the story, the design team conducted pre-interviews with the older adults who expressed interest in appearing in the video. Pre-interview questions were prepared by the VE members in consultation with CRs to ensure they captured MHL and PC. These pre-interviews were conducted individually by one VE member (JS) in January, 2026. Older adults described their experiences with pre-interviews as positive and engaging: “I appreciated the questions and I felt like it was a conversation” (OA). Subsequently, the VEs developed a storyline that outlined a possible narrative and key messages for the video. They then presented it at our fifth meeting to gather feedback and ensure that it aligned with our team discussions and research evidence: “So this is everyone's opportunity to hear the story that we've put together and then add everyone's opinions, thoughts, concerns, comments” (VE).

This storyline involved a story arc capturing the strengths focused message for the final video, and involved multiple stories, a broad range of mental health challenges, examples of functional impairment, emotional impact, and research targets (PC and MHL). During the discussion, an important theme emerged that our team agreed should be included in our final video: *navigating the mental health care system*. Older adults emphasized that navigating this system is not easy, and the first step towards seeking help can look different for each person. Therefore, our team decided that it was important to convey the message that reaching out for help may not be successful on the first try; individuals might need to attempt to contact several professionals before finding the right fit for their needs. To illustrate this, our older adult team members agreed to share their stories of navigating the mental health care system and their initial steps toward asking for help in the final video intervention.

***First draft of the video and animation.*** Between February and March 2026, on-camera interviews were conducted with our four OA members for the final video intervention. One of the on-camera interviews had to be rescheduled, which incurred additional costs that our grant funding could not cover. The VE team ultimately offered to cover these extra expenses which likely would not have been possible without the meaningful relationships and strong sense of collaboration established through this co-design process.

In the subsequent co-design meeting, the video-design experts shared the first draft of the video intervention with the team. Reactions to the draft video were emotional, with team members expressing appreciation for how well the VEs weaved the different stories together and captured the advice and suggestions from our group discussions. Importantly, the emotional responses reflected gratitude and appreciation for our older adults' willingness to share their vulnerable experiences on-screen for this project, and how doing so will help others facing similar challenges. Only minor feedback was provided regarding the use of a clip in which an older adult team member referenced a character from an older film, as it may not be widely relevant to viewers. In response, video design experts indicated that they would replace it with an alternative clip to retain the intended message and narrative.

During this sixth meeting, our team also dedicated most of the time to finalize decisions about the animation elements for the final video. An animator from the video production company joined us to discuss some preliminary animation concepts she had been considering. In particular, she talked about the idea of using a silhouette character in the video to enhance the storyline, allowing viewers to see themselves within the silhouette as the story unfolds. Team members liked this idea, but also provided feedback regarding the silhouette character as being "bulky" and appearing masculine and young, which could make it harder for older adults to

identify with. Suggestions included emphasizing the importance of incorporating other animation elements, such as hands which can convey messages symbolically, making them broadly applicable across audiences. With further discussion, the team reached a consensus to use both silhouettes (neutral and depicting older adults) when needed to illustrate full scenarios in the video, and to use hands and other animation elements for additional components of the video: “I think maybe a balance of the hands and a silhouette might be a consensus” (VE). Based on the feedback received, the VEs created new animation designs for review and feedback during our penultimate meeting. All team members agreed that these updated animations reflected their suggestions and fit the video appropriately.

As outlined in checklist item 2.10 in Table 1, our co-design process involved cycles of iterative feedback to ensure that the final video reflected the input of all team members. The result of this process culminated in the eighth and final team meeting, during which the video team screened the final video intervention for all team members to view together. Following the screening, we celebrated the completion of the development stage by sharing lunch and cutting a celebratory cake.

## **Evaluation**

As presented in Table 1, this stage involves both process and outcome evaluation. Process evaluation includes ongoing assessment of team members' satisfaction and their perceived contributions to the project (checklist item 3.1). It also emphasizes plans for disseminating results to the public (checklist item 3.2). In contrast, outcome evaluation is concerned with the validity of the final outcome, and future plans to test the intervention's effectiveness (checklist items 3.4 & 3.5).

**Process evaluation.** Using two different methods, we evaluated team members'

satisfaction with the process and their perceived contribution towards the overall project. First, we utilized valid and reliable 6-item patient engagement and evaluation tool (PEET-6; Moore, 2022) to evaluate perceived satisfaction of team members and quality of our collaborative engagement throughout the co-design process. Second, we kept records of attendance to reflect engagement among team members (Leask et al., 2019).

***PEET-6 surveys.*** During our first meeting, we introduced our team members to the PEET-6 and discussed that we will be ending each session by having all team members (CRs, VEs, and OAs) complete it anonymously, and then start the following session with a review of scores. The aim of this was to use a brief measure to assess the degree to which team members felt trust, respect, fairness, competency, legitimacy, and accountability in the co-design process, which aligns with the principles of authentic rather than tokenistic partnership (Collins et al., 2018; Moore, 2022). Scores of 4-7 on each item were interpreted as indicating good to high perceived satisfaction.

Given the small sample size, statistical comparisons were not considered appropriate. Instead, survey data were examined visually to monitor changes in mean scores of individual items. We also examined the range of responses to ensure that individual perspectives were not obscured by averages, and that all team members' experiences were represented. Across our meetings, the mean scores for each item indicated that collaborative engagement remained consistently high. However, in the first meeting, there were three scores of 3 on three individual items, and during the second meeting, there was one score of 3 on one item. These scores were discussed non-defensively in subsequent meetings. The reason for these lower ratings was that there was less time for group discussion in the preliminary meetings where CRs presented information about CBPR and prior research related to stigma interventions. The PEET-6 also

provides space for open-ended feedback after each item, which was incorporated into our meetings. For example, one team member requested agendas in advance, and accordingly, we started emailing agendas a few days before our co-design meetings. The item-level PEET-6 results for each meeting are presented in Table 3. Notably, the PEET-6 was not administered at the eighth meeting, as this meeting focused on celebrating the completion of the intervention-development stage.

***Attendance logs.*** One of the key challenges of this process can be coordinating everyone's schedules for the co-design meetings. Although we were very successful in scheduling meetings by aligning everyone's availability, resulting in high attendance rates, there were a few instances in which some team members were unable to attend due to scheduling conflicts. We maintained attendance logs to document any team members who could not attend these meetings throughout our process (see Table 4). Importantly, these attendance records indicated 100% retention rates reflecting high engagement, loyalty, and perceived satisfaction of our team members with this process.

In addition to tracking attendance, we implemented strategies to support consistent and seamless participation of team members in all meetings. For example, one older adult team member was out of town for three meetings, so they were provided with secured zoom link in advance to facilitate their participation. Further, when team members were unable to attend co-design meetings, they were provided with updates through follow-up meetings, or through Rev generated summaries to facilitate meaningful engagement in our co-design meetings.

Additionally, we ensured that participating in co-design meetings did not impose any additional financial burden on our OA members (Smith et al., 2020). Therefore, all team members were asked throughout the co-design process whether they required transportation

support, including bus passes, taxi vouchers, or parking tickets. OAs who requested support were provided with bus passes or taxi vouchers as appropriate.

Concerning checklist item 3.2, the final developed intervention was shown to all team members during our last meeting. Further, in addition to providing this manuscript to team members for review and feedback, we also presented our co-design process at institutional and national level conferences (Kaur et al., 2026a; Kaur et al., 2026b).

In addition to evaluating team members' perceived satisfaction with the process, we also engaged in ongoing member checking throughout our co-design process to ensure that the emerging key ideas and components of the intervention accurately reflected our discussions and the perspectives of team members (checklist item 3.3). At the beginning of each meeting, team members were presented with a brief oral summary of the previous meeting. This provided everyone with the opportunity to add any additional points or share their thoughts. During the fourth meeting, all team members were provided with Rev summary sheets of all previous meetings highlighting key themes from the earlier discussions. We then openly discussed these themes, allowing team members to reflect on what had been gathered so far and to introduce any additional thoughts or ideas they wanted to address:

In this meeting we wanted to just slow down and revisit our discussion during our last two meetings and see if there were any things which we've missed or if there are any gaps or if somebody would add to it. (CR)

**Outcome.** The main outcome of this process was our co-designed anti-stigma intervention for older adults. This intervention was developed through multiple iterations, incorporating feedback from all team members, ensuring it aligns with both the research evidence, and the lived experiences and needs of older adults.

***Future plans.*** Following the success of our co-design process, we have three next steps planned. First, we plan to conduct a feasibility study with older adults not involved in this study by hosting a community event where we will screen the developed intervention video, followed by a panel discussion with members of our team. Second, immediately following the eighth and final group meeting we will interview all team members to explore their experiences of participating in the co-design process, as well as the impact this project has had on them. Third, in the summer and fall of 2026 we will start recruitment of a randomized controlled trial of the developed intervention, comparing it to both an empty control group and a standard control intervention. We have already secured funding for this trial. During our penultimate meeting, we informed all co-design team members about these next steps and invited them to participate in the research process, in various capacities that suit their needs to respect the principle of shared ownership.

### **Critical Reflection & Discussion**

This manuscript documents the development process of an anti-stigma intervention that is rooted in scientific theory and informed by the lived experiences of older adults. To our knowledge, this is the first anti-stigma intervention developed to reduce internalized stigma of seeking help specifically for older adults using co-design methods. Further, many co-design studies have not clearly detailed their intervention development processes (Kilfoy et al., 2024; Slattery et al., 2020). Without this documentation it is impossible to know the extent to which end-users have been involved in the process on a continuum ranging from full engagement to tokenistic involvement. In contrast, we not only provided a clear outline of our intervention development process but also utilized structured co-design guidelines to guide and report on this process (Leask et al., 2019). Importantly, we also evaluated our co-design process using different

methods, which remains uncommon in existing co-design studies (Kilfoy et al., 2024; Westworth et al., 2025).

Throughout this process, we focused on cultivating the principles of trust and respect (Collins et al., 2018; Khan et al, 2025). This is reflected in the willingness of older adult team members to openly share their lived experiences throughout the co-design process, trusting that their perspectives would be respected, valued, and validated. Furthermore, the willingness of older adults in sharing their lived experiences on camera and appearing in the final video speaks to the trust, safety, and sense of empowerment cultivated within this co-design process (Sacre & Godfrey, 2026):

I want to say that when I started this project, I had no idea if I fit in, if I had anything to offer or what this was going to be about. I have experienced an incredibly positive group. This has been a growth. It's kind of helped us or helped me from going through my experiences and sharing them....., so we've all had to be pretty vulnerable. But going through those experiences to see what this is, and feeling like it was all for a reason. (OA)

Importantly, our study shows how research evidence, lived experiences, and creative expertise can be brought together and integrated, directly speaking to the principle of equitable collaboration (Collins et al., 2018). In our intervention development process, researchers and clinicians emphasized developing an evidence-based intervention targeting PC and MHL, while our older adult team members discussed their lived experiences, preferences, and needs to ensure that the video intervention is relevant to the intended audience. Meanwhile, our creative team utilized their expertise in video design to ensure that the final video intervention is engaging and effectively captures all the essential elements. Throughout the process, all team members willingly shared their skills and expertise with each other to collaboratively develop this video

intervention (Leask et al, 2019; Sacre & Godfrey, 2026). Not surprisingly, balancing team members with different expertise comes with its own set of challenges. Below are some of our key reflections that we hope will be of use to other researchers interested in co-developing interventions with older adults.

First, we believe that careful recruitment contributed significantly to the success of collaborative engagement throughout our process (Leask et al., 2019; Zogas et al., 2024). During recruitment, it is important not only to ensure that individuals feel comfortable sharing their input during group discussions, but also that the group reflects diverse perspectives in terms of socioeconomic status, educational background, lived experiences, gender identity, and ethnicity. This is particularly important when the long-term goal is to scale the intervention to a broader population (Leask et al., 2019). Through our recruitment efforts, we were able to include one male older adult and one older adult team member from a racialized group. Further, attention to the size of the co-design group is equally important to ensure that each member has an opportunity to contribute. Prior research suggests an ideal size of co-design teams of 10-12 (Fix et al., 2024; Leask et al., 2019) and our experience with a team of 11 supports this recommendation.

Second, our experiences reinforced the importance of actively addressing power dynamics rather than avoiding them, or assuming that they do not exist (Collins et al., 2018; Kilfoy et al., 2024). Constant attention and efforts aimed at relationship building and de-emphasizing power hierarchies helped us ensure that all team members had meaningful opportunities to contribute. We believe that including OA advocates was beneficial as they brought strong voices into the room. This may have also helped other OAs feel more comfortable engaging in the process and sharing their thoughts and opinions freely. Similarly, this may be an

important consideration for other co-design teams working with marginalized groups that are often overlooked in society to create more inclusive and supportive environment to help equitable participation.

Third, it is important to ensure that all individuals involved in the co-design process feel heard, valued, and recognized as meaningful members of the team. It should not be assumed that the perspectives of more actively contributing and vocal team members reflect the experiences of the entire group. For example, although the average PEET-6 scores across meetings were consistently high, we paid close attention to the range of scores on each item to identify and address any individual concerns that may have been overlooked by the average scores alone. In addition, research assistant informally checked in with community members after each meeting to provide opportunities for one-on-one conversations about thoughts, concerns, or ideas they may not have felt comfortable sharing within the larger group. Altogether, these small but intentional actions helped foster an environment in which team members felt safe, heard, and validated throughout the co-design process (Rheinberger et al., 2026), without making assumptions about their experiences.

Fourth, researchers need to be intentional about the co-design process to foster true collaborative engagement among team members. We achieved this by paying close attention to the group dynamics using field notes. The first author also took reflexive notes to help identify any biases as they arose to ensure the true power sharing throughout. For example, during our first meeting, we noticed that all of the OAs sat on one side of the room, while all the CRs sat on the other. This was concerning, as it suggested the potential to create an “us versus them” situation rather than fostering true collaborative engagement. To address this, we discussed the need to be more intentional about our seating arrangements during our weekly meetings. In our

next co-design meeting, we encouraged CRs to spread out around the table and this had the intended effect of promoting equitable team relationships.

Our reflective notes from the first meeting highlighted how easy it can be to lose the sense of genuine collaboration, especially when researchers and clinicians dominate the process. Although opportunities for collaboration were reduced in the first meeting where the research team outlined goals for the project and provided education about CBPR, co-design methods and prior research related to stigma interventions, lower PEET-6 ratings for this session emphasized how important it was that we attend to it moving forward. During our discussions in weekly research meetings, we emphasized the necessity of being more intentional in our approach and finding ways to integrate and value all forms of knowledge. Consequently, our goal shifted from leading the project to facilitating the emergence and integration of various forms of knowledge and expertise to develop this intervention. These efforts became evident in our subsequent meetings as team members appeared to be more comfortable with each other. Facilitators found themselves more focused on ensuring discussions remained relevant and that agenda items were addressed, rather than initiating the discussions themselves. All these changes in group dynamics were captured by reflexive notes, field notes, and PEET-6 scores.

Finally, it is plausible that the success of the co-design process relies heavily on researchers, especially their interpersonal skills. In this project, both lead researchers were warm, engaging, open, and receptive to others' perspectives which helped foster an environment in which team members felt safe and comfortable in sharing their viewpoints and vulnerable mental health experiences. Further, we believe that researcher's identities and lived experiences also matter in shaping the co-design process. For example, the lead author of this project is a South Asian immigrant woman from a low socioeconomic background. Her underprivileged

background and lived experiences contributed to her heightened awareness of power dynamics and her intentional efforts to address them throughout this process. Besides, it is important not only to document group dynamics and areas for improvement following each co-design meeting, but also to revisit these reflections before subsequent meetings. Doing so can help researchers remain mindful of previously identified challenges and reduce the likelihood of repeating the same issues across sessions. Importantly, the lead research team members' motivation and commitment to fostering genuine collaboration, as well as their trust in the co-design process, its principles, and team members' expertise in intervention development, are invaluable.

Drawing on the key lessons and experiences from our co-design process, we developed a set of recommendations based on our experiences concerning various stages of the process, including planning, conducting, and evaluation (see Table 5).

### **Limitations and Challenges**

Although our collaborative engagement was successful, it also had several limitations. First, despite our efforts to recruit a diverse group of older adults, three of our five older adult team members were White women. Having a more diverse group may have brought a broader range of lived experiences and perspectives into the intervention development process. Further, two CRs served as co-facilitators during all meetings. In retrospect, it might have been helpful to have an OA co-facilitator as well.

Another limitation of our co-design process was that it was time-consuming. We met as a large group for eight 90-minute group meetings (12 hours), plus additional research team meetings, over the course of about 10 months, starting from the approval of our SSHRC grant in July 2025 to the final meeting in June 2026, where we presented the final version of the video intervention to all team members. Additionally, the process was expensive; we hired a research

assistant to help with project-related tasks such as coordinating team members and scheduling meetings. We also hired a well-known video production company to create our video intervention. Fortunately, we were able to secure funding to support these expenses. The ability of teams to engage in this process without grant support and resources is a limitation well-documented by others (Baldwin et al., 2018; Slattery et al., 2020).

A challenge we encountered during the initial planning stages was that although we were committed to the idea of co-designing, we found it challenging and overwhelming to determine which framework was appropriate for our research. There are at least over 25 different frameworks available for conducting this type of research (Vaughn & Jacquez, 2020) and the various frameworks use different terminology for similar concepts, such as co-production, co-design, co-creation, patient engagement, human-centered design (Sacre & Godfrey, 2026; Silvola et al., 2023). This challenge was further compounded by the limited availability of methodological guidelines (Leask et al., 2019; Zogas et al., 2024) and the lack of structured, transparent documentation of existing co-designed video interventions to guide our co-design process for intervention development.

It is not surprising that the complex literature on co-design can create challenges for novice researchers trying to engage end-users in their research. Therefore, we see a pressing need to consolidate the existing literature on co-design and help future researchers in streamlining their processes for involving end-users in their work. Additionally, as demonstrated in our paper, it is crucial for researchers to document their intervention development processes using structured guidelines to ensure transparency, and aid other researchers.

## **Conclusion**

Despite the limitations and challenges of co-design, there is significant value in involving

end-users in the research process (Sacre & Godfrey, 2026; Zogas et al., 2024). For example, CRs and VEs from our team were younger and middle-aged adults. If they developed this intervention on their own, it is likely that they may have missed the needs and preferences of OAs. We strongly believe that this intervention is impactful because of the valuable insights that older members brought to the team. Through discussions about the language used to describe specific disorders, multiple stories, video formats, call-to-action resources and more, older adults' contributions were essential. Furthermore, our older team members' participation in the video intervention to discuss their mental health experiences was invaluable. If it were not for this approach, we might have faced significant challenges in recruiting older adults to appear in the video, or we may have had to hire actors.

Thus, following the footsteps of other co-design researchers, we highly encourage researchers to engage in co-design methodologies (Baldwin et al. 2018, Khan et al., 2025; Leask et al., 2019; Palmer et al., 2019; Sacre & Godfrey, 2026; Slattery et al., 2020; Zogas et al, 2024). Not only does it benefit the research process, but it also empowers end-users and aids in the dissemination of research findings directly within the community (Slattery et al., 2020). Working closely with marginalized groups such as older adults in this capacity can also help build their trust in the research process (Khan et al., 2025).

Overall, our co-design process demonstrated how different areas of expertise can be combined to create meaningful interventions, and how the principles of authentic partnership can be enacted throughout. Further, we encourage researchers to adopt structured reporting guidelines to document the co-design process. This practice will help advance the field and ensure adherence to the principles of genuine collaboration, preventing it from becoming tokenistic. Further, we hope that our key takeaways can support other researchers in

implementing authentic collaborative engagement with growing numbers of older adults who both need resources such as the one we developed, and who can add to their impact.

### References

- Adams, C., Gringart, E., & Strobel, N. (2023). Barriers to mental health help-seeking among older adults with chronic diseases. *Australian Psychologist*, 59(2), 154–165.  
<https://doi.org/10.1080/00050067.2023.2282540>
- Baldwin, J. N., Napier, S., Neville, S., & Wright-St Clair, V. A. (2018). Impacts of older people's patient and public involvement in health and social care research: A systematic review. *Age and Ageing*, 47(6), 801–809. <https://doi.org/10.1093/ageing/afy092>
- Brenner, R. E., Colvin, K. F., Hammer, J. H., & Vogel, D. L. (2021). Using item response theory to develop revised (SSOSH-7) and ultra-brief (SSOSH-3) self-stigma of seeking help scales. *Assessment*, 28(5), 1488–1499. <https://doi.org/10.1177/1073191120958496>
- Byers, A. L., Arian, P. A., & Yaffe, K. (2012). Low use of mental health services among older Americans with mood and anxiety disorders. *Psychiatric Services (Washington, D.C.)*, 63(1), 66–72. <https://doi.org/10.1176/appi.ps.201100121>
- Collins, S. E., Clifasefi, S. L., Stanton, J., The Leap Advisory Board, Straits, K. J. E., Gil-Kashiwabara, E., Rodriguez Espinosa, P., Nicasio, A. V., Andrasik, M. P., Hawes, S. M., Miller, K. A., Nelson, L. A., Orfaly, V. E., Duran, B. M., & Wallerstein, N. (2018). Community-based participatory research (CBPR): Towards equitable involvement of community in psychology research. *American Psychologist*, 73(7), 884–898.  
<https://doi.org/10.1037/amp0000167>
- Conner, K. O., McKinnon, S. A., Roker, R., Ward, C. J., & Brown, C. (2018). Mitigating the stigma of mental illness among older adults living with depression: The benefit of contact with a peer educator. *Stigma and Health (Washington, D.C.)*, 3(2), 93–101.  
<https://doi.org/10.1037/sah0000076>

- Corrigan, P. W., Morris, S. B., Michaels, P. J., Rafacz, J. D., & Rüsch, N. (2012). Challenging the public stigma of mental illness: A meta-analysis of outcome studies. *Psychiatric Services (Washington, D.C.)*, 63(10), 963-973. <https://doi.org/10.1176/appi.ps.201100529>
- Elshaikh, U., Sheik, R., Saeed, R. K. M., Chivese, T., & Alsayed Hassan, D. (2023). Barriers and facilitators of older adults for professional mental health help-seeking: A systematic review. *BMC Geriatrics*, 23(1), 516. <https://doi.org/10.1186/s12877-023-04229-x>
- Fix, G. M., Kaitz, J., Herbst, A. N., Wiener, R. S., Crocker, D., Miano, D., & Barker, A. M. (2024). Practical strategies for co-design: The case of engaging patients in developing patient-facing shared-decision making materials for lung cancer screening. *Journal of Patient Experience*, 11, 23743735241252247. <https://doi.org/10.1177/23743735241252247>
- Jorm, A. F. (2000). Mental health literacy: Public knowledge and beliefs about mental disorders. *The British Journal of Psychiatry*, 177(5), 396-401.
- Kaur, J., Mackenzie, C. S., Koven, L., Reynolds, K., & HOPE Team (2026a, May 07). *Co-designed intervention to reduce internalized stigma of seeking mental health services for older adults: A community-based participatory research approach (HOPE project)* [Poster presentation]. Centre on Aging's 43<sup>rd</sup> Annual Spring Research Symposium, University of Manitoba, Winnipeg, MB, Canada.
- Kaur, J., Mackenzie, C. S., Koven, L., Reynolds, K., & HOPE Team (2026b, June 4-6). *Co-designed intervention to reduce internalized stigma of seeking mental health services for older adults: A community-based participatory research approach (HOPE project)* [Oral presentation]. The Canadian Psychological Association (CPA) 87th Annual National Convention, Montreal, QC, Canada.

- Khan, N., Keck, L., Sykes, C., Rowden, C., Simister, J., Fenlon, S., Mccallum, E., Bell, M., Whiting, D., Shelton, C., Wells, G., Giles, R., Howard, J., & Peckham, S. (2025). Diversity, community engagement and co-design in research: A rapid review. *BMJ Leader*, 9(3), 325–330. <https://doi.org/10.1136/leader-2024-001046>
- Kilfoy, A., Hsu, T.-C. C., Stockton-Powdrell, C., Whelan, P., Chu, C. H., & Jibb, L. (2024). An umbrella review on how digital health intervention co-design is conducted and described. *NPJ Digital Medicine*, 7(1), Article 374. <https://doi.org/10.1038/s41746-024-01385-1>
- Lavingia, R., Jones, K., & Asghar-Ali, A. A. (2020). A systematic review of barriers faced by older adults in seeking and accessing mental health care. *Journal of Psychiatric Practice*, 26(5), 367-382. <https://doi.org/10.1097/PRA.0000000000000491>
- Leask, C. F., Sandlund, M., Skelton, D. A., Altenburg, T. M., Cardon, G., Chinapaw, M. J. M., De Bourdeaudhuij, I., Verloigne, M., & Chastin, S. F. M. (2019). Framework of principles and recommendations for utilising participatory methodologies in the co-creation and evaluation of public health interventions. *Research Involvement and Engagement*, 5(2). <https://doi.org/10.1186/s40900-018-0136-9>
- Mackenzie, C. S., Del Rosario, N., & Krook, M. (2022). Stigma of seeking mental health services and related constructs in older versus younger adults. In *The Cambridge Handbook of Stigma and Mental Health* (pp. 326–346).
- Mackenzie, C. S., Heath, P. J., Vogel, D. L., & Chekay, R. (2019). Age differences in public stigma, self-stigma, and attitudes toward seeking help: A moderated mediation model. *Journal of Clinical Psychology*, 75(12), 2259–2272. <https://doi.org/10.1002/jclp.22845>
- Mackenzie, C. S., Krook, M. A., Murphy, D. J., & Rapaport, L. elle. (2025). Mental health literacy reduces the impact of internalized stigma on older adults' attitudes and intention

to seek mental health services. *Clinical Gerontologist*, 1–13.

<https://doi.org/10.1080/07317115.2024.2408762>.

Mackenzie, C. S., Pagura, J., & Sareen, J. (2010). Correlates of perceived need for and use of mental health services by older adults in the collaborative psychiatric epidemiology surveys. *The American Journal of Geriatric Psychiatry*, 18(12), 1103–1115.

<https://doi.org/10.1097/JGP.0b013e3181dd1c06>

Mackenzie, C. S., & Pankratz, L. (2025). Perceived need, mental health literacy, neuroticism and self- stigma predict mental health service use among older adults. *Clinical Gerontologist*, 48(1), 161–174. <https://doi.org/10.1080/07317115.2022.2058440>

Mackenzie, C. S., Reynolds, K., Cairney, J., Streiner, D. L., & Sareen, J. (2012). Disorder-specific mental health service use for mood and anxiety disorders: Associations with age, sex, and psychiatric comorbidity. *Depression and Anxiety*, 29(3).

<https://doi.org/10.1002/da.20911>

Makhmud, A., Thornicroft, G., & Gronholm, P. C. (2022). Indirect social contact interventions to reduce mental health-related stigma in low- and middle-income countries: Systematic review. *Epidemiology and Psychiatric Sciences*, 31, e79.

<https://doi.org/10.1017/S2045796022000622>

Marrone, N. L., Nieman, C. L., & Coco, L. (2022). Community-based participatory research and human-centered design principles to advance hearing health equity. *Ear and Hearing*, 43(Suppl 1), 33S–44S. <https://doi.org/10.1097/AUD.0000000000001183>

Moore, A., Wu, Y., Kwakkenbos, L., Silveira, K., Straus, S., Brouwers, M., Grad, R., & Thombs, B. D. (2022). The patient engagement evaluation tool was valid for clinical practice guideline development. *Journal of Clinical Epidemiology*, 143, 61–72.

<https://doi.org/10.1016/j.jclinepi.2021.11.034>

Morrow-Howell, N., Galucia, N., & Swinford, E. (2020). Recovering from the COVID-19 pandemic: A focus on older adults. *Journal of Aging & Social Policy*, 32(4–5), 526–535.

<https://doi.org/10.1080/08959420.2020.1759758>

Murphy, D. J., Mackenzie, C. S., Dryden, R. P., & Hamm, J. M. (2024). Perceived control moderates the internalized stigma model of seeking mental health services in distressed older adults. *Journal of Counseling Psychology*, 71(5), 473-486.

<https://doi.org/10.1037/cou0000733>

Palmer, V. J., Weavell, W., Callander, R., Piper, D., Richard, L., Maher, L., Boyd, H., Herrman H., Furler, J., Gunn, J., Iedema, R., & Robert, G. (2019). The participatory zeitgeist: An explanatory theoretical model of change in an era of coproduction and codesign in healthcare improvement. *Medical Humanities*, 45(3), 247– 257.

<https://doi.org/10.1136/medhum-2017-011398>

Pepin, R., Segal, D. L., & Coolidge, F. L. (2009). Intrinsic and extrinsic barriers to mental health care among community-dwelling younger and older adults. *Aging & Mental Health*, 13(5), 769–777. <https://doi.org/10.1080/13607860902918231>

Pescosolido, B. A., & Olafsdottir, S. (2013). Beyond dichotomies: Confronting the complexity of how and why individuals come or do not come to mental health care. *World Psychiatry*, 12(3), 269–271. <https://doi.org/10.1002/wps.20072>

Public Health Agency of Canada. (2020, February). *Evidence summary: Interventions to address stigma in the health system*. Government of Canada. <https://www.canada.ca/en/public-health/corporate/publications/chief-public-health-officer-reports-state-public-health-canada/evidence-summary-interventions-address-stigma-health-system.html>

- Reynolds, K., Medved, M., Mackenzie, C. S., Funk, L. M., & Koven, L. (2020). Older adults' narratives of seeking mental health treatment: Making sense of mental health challenges and "muddling through" to care. *Qualitative Health Research*, 30(10), 1517-1528. <https://doi.org/10.1177/1049732320919094>
- Reynolds, K., Pietrzak, R. H., El-Gabalawy, R., Mackenzie, C. S., & Sareen, J. (2015). Prevalence of psychiatric disorders in U.S. older adults: Findings from a nationally representative survey. *World Psychiatry*, 14(1), 74–81. <https://doi.org/10.1002/wps.20193>
- Rheinberger, D., Boydell, K., Armstrong, S. O., Lessing, J., Pollard, S. A., Jacob, I., McGillivray, L., Elder, E., & Shand, F. (2026). Co-designing suicide prevention research with mothers of suicidal adolescents – applying McKercher's Model of Care. *Research Involvement and Engagement*, 12(1), Article 32. <https://doi.org/10.1186/s40900-026-00863-y>
- Rothbaum, F., Weisz, J. R., & Snyder, S. S. (1982). Changing the world and changing the self: A two-process model of perceived control. *Journal of Personality and Social Psychology*, 42(1), 5.
- Sacre, A., & Godfrey, A. (2026). Co-designing the future: End-user involvement in digital interventions. *NPJ Digital Medicine*, 9(1), Article 160. <https://doi.org/10.1038/s41746-026-02444-5>
- Silvola, S., Restelli, U., Bonfanti, M., & Croce, D. (2023). Co-design as enabling factor for patient-centred healthcare: A bibliometric literature review. *ClinicoEconomics and Outcomes Research*, 15, 333-347. <https://doi.org/10.2147/CEOR.S403243>
- Sirey, J. A., Bruce, M. L., & Alexopoulos, G. S. (2005). The Treatment Initiation Program: An

- intervention to improve depression outcomes in older adults. *The American Journal of Psychiatry*, 162(1), 184–186. <https://doi.org/10.1176/appi.ajp.162.1.184>
- Sirey, J. A., Woods, A., Solomonov, N., Evans, L., Banerjee, S., Zhanotti, P., Alexopoulos, G., & Kales, H. C. (2020). Treatment adequacy and adherence as predictors of depression response in primary care. *The American Journal of Geriatric Psychiatry : Official Journal of the American Association for Geriatric Psychiatry*, 28(11), 1164–1171.
- Slattery, P., Saeri, A. K., & Bragge, P. (2020). Research co-design in health: A rapid overview of reviews. *Health Research Policy and Systems*, 18(1), Article 17. <https://doi.org/10.1186/s12961-020-0528-9>
- Smith, S., Winkler, S., Towne, S., & Lutz, B. (2020). Utilizing CBPR charrette in community-academic research partnerships – What stakeholders should know. *Journal of Participatory Research Methods*, 1(1). <https://doi.org/10.35844/001c.13179>
- Speerforck, S., & Schomerus, G. (2020). Social milieu: A relevant concept for a better understanding of stigma and help-seeking?. *Der Nervenarzt*, 91, 785-791.
- Storr, W. (2020). *The Science of Storytelling: Why Stories Make Us Human and How to Tell Them Better* (1st ed.). Abrams, Inc.
- Suzuki, W. A., Feliú-Mójer, M. I., Hasson, U., Yehuda, R., & Zarate, J. M. (2018). Dialogues: The Science and Power of Storytelling. *The Journal of Neuroscience*, 38(44), 9468–9470. <https://doi.org/10.1523/JNEUROSCI.1942-18.2018>
- Thorburn, K., Waks, S., Aadam, B., Fisher, K. R., Spooner, C., & Harris, M. F. (2024). Creating the conditions for collaborative decision-making in co-design. *Co Design*, 20(4), 567–584. <https://doi.org/10.1080/15710882.2024.2349578>
- Tam, T. (2020). Aging and chronic diseases: A profile of Canadian seniors.

[https://www.canada.ca/content/dam/hc-sc/documents/services/publications/diseases-and-conditions/aging-chronic-diseases/canadian-seniors-report\\_2021-eng.pdf](https://www.canada.ca/content/dam/hc-sc/documents/services/publications/diseases-and-conditions/aging-chronic-diseases/canadian-seniors-report_2021-eng.pdf)

Thornicroft, G., Mehta, N., Clement, S., Evans-Lacko, S., Doherty, M., Rose, D., Koschorke, M., Shidhaye, R., O'Reilly, C., & Henderson, C. (2016). Evidence for effective interventions to reduce mental-health-related stigma and discrimination. *The Lancet (British Edition)*, 387(10023), 1123–1132. [https://doi.org/10.1016/S0140-6736\(15\)00298-6](https://doi.org/10.1016/S0140-6736(15)00298-6)

Thornicroft, G., Sunkel, C., Aliev, A. A., Baker, S., Brohan, E., el Chammay, R., Davies, K., Demissie, M., Duncan, J., Fekadu, W., Gronholm, P. C., Guerrero, Z., Gurung, D., Habtamu, K., Hanlon, C., Heim, E., Henderson, C., Hijazi, Z., Hoffman, C., Hosny, N.,...Winkler, P. (2022). The Lancet Commission on ending stigma and discrimination in mental health. *The Lancet*, 400(10361), 1438-1480. [https://doi.org/10.1016/S0140-6736\(22\)01470-2](https://doi.org/10.1016/S0140-6736(22)01470-2)

Vaughn, L. M., & Jacquez, F. (2020). Participatory research methods – Choice points in the research process. *Journal of Participatory Research Methods*, 1(1). <https://doi.org/10.35844/001c.13244>

Viswanathan, M., Ammerman, A., Eng, E., Garlehner, G., Lohr, K. N., Griffith, D., Rhodes, S., Samuel-Hodge, C., Maty, S., Lux, L., Webb, L., Sutton, S. F., Swinson, T., Jackman, A., & Whitener, L. (2004). Community-based participatory research: Assessing the evidence. *Evidence Report/Technology Assessment (Summary)*, (99), 1–8.

Vogel, D.L., Wade, N.G. and Hackler, A.H. (2007). Perceived public stigma and the willingness to seek counseling: The mediating roles of self-stigma and attitudes toward counselling. *Journal of Counselling Psychology*, 54, 40-50. <http://dx.doi.org/10.1037/0022-0167.54.1.40>

- Vogel, D. L., Zhao, N., Vidales, C. A., Brenner, R. E., Heath, P. J., Hammer, J. H., & Wade, N. G. (2024). Extending the Theoretical Understanding of Mental Illness and Help-Seeking Self-Stigmas. *Stigma and Health (Washington, D.C.)*.  
<https://doi.org/10.1037/sah0000570>
- Wallerstein, N., Duran, B., Oetzel, J. G., & Minkler, M. (2017). *Community-based participatory research for health: Advancing social and health equity* (Third edition). Wiley.
- Wallerstein, N. (2021). Engage for equity: Advancing the fields of community-based participatory research and community-engaged research in community psychology and the social sciences. *American Journal of Community Psychology*, 67(3–4), 251–255.  
<https://doi.org/10.1002/ajcp.12530>
- Westworth, S. E., Lu, A., Long, K. M., & Andrew, N. E. (2025). Evaluating co-design processes used in the development of healthcare interventions in residential aged care: A scoping review. *Journal of Public Health*, 47(4), 814–827.  
<https://doi.org/10.1093/pubmed/fdaf111>
- Wong, E. C., Collins, R. L., Cerully, J. L., Yu, J. W., & Seelam, R. (2018). Effects of contact-based mental illness stigma reduction programs: age, gender, and Asian, Latino, and White American differences. *Social Psychiatry and Psychiatric Epidemiology*, 53(3), 299–308. <https://doi.org/10.1007/s00127-017-1459-9>
- World Health Organization. (2023, October 20). *Mental health of older adults*.  
<https://www.who.int/news-room/fact-sheets/detail/mental-health-of-older-adults>
- Wuthrich, V. M., & Frei, J. (2015). Barriers to treatment for older adults seeking psychological therapy. *International Psychogeriatrics*, 27(7), 1227–1236.  
<https://doi.org/10.1017/S1041610215000241>

Xu, Z., Huang, F., Kösters, M., Staiger, T., Becker, T., Thornicroft, G., & Rüsch, N. (2018).

Effectiveness of interventions to promote help-seeking for mental health problems:

Systematic review and meta-analysis. *Psychological Medicine*, 48(16), 2658–2667.

doi:10.1017/S0033291718001265

Yau, J. H.-Y., Wong, E. L. Y., Kanagawa, H. S., Liu, T., Wong, G. H. Y., & Lum, T. Y. S.

(2024). Effectiveness of community-based participatory research (CBPR) interventions

on mental health outcomes: A systematic review. *Social Science & Medicine (1982)*, 363,

Article 117491. <https://doi.org/10.1016/j.socscimed.2024.117491>

Zhao, X., Zhang, L., Sáenz, A. A., Zhang, X., Sun, J., Zhong, Q., Cheng, Y., & Jia, Y. (2024).

Prevalence of subthreshold depression in older adults: A systematic review and meta-analysis. *Asian Journal of Psychiatry*, 102, 104253.

<https://doi.org/10.1016/j.ajp.2024.104253>

Zogas, A., Sitter, K. E., Barker, A. M., Fix, G. M., Khanna, A., Herbst, A. N., & Vimalananda,

V.G. (2024). Strategies for engaging patients in co-design of an intervention. *Patient*

*Education and Counseling*, 123, 108191. <https://doi.org/10.1016/j.pec.2024.108191>

**Table 1***Revised Checklist for Reporting Intervention Co-Design (Leask et al., 2019)*

| <b>Section</b> | <b>Subsections</b>                              | <b>Checklist Item</b>                                                                           |
|----------------|-------------------------------------------------|-------------------------------------------------------------------------------------------------|
| 1. Planning    | a. Framing of Study Aims                        | 1. Define the problem, objective, specific participatory framework used, and co-creators        |
|                |                                                 | 2. Explain the sampling criteria                                                                |
|                | b. Recruitment Procedure                        | 3. Describe recruitment settings                                                                |
|                |                                                 | 4. How many individuals engaged as co-creators (academic / non-academic stakeholders)?          |
|                |                                                 | 5. Describe the co-design team members                                                          |
| 2. Conducting  | a. Structure of Co-Design Meetings              | 1. Describe the frequency and duration of co-design meetings                                    |
|                | b. Manifesting Collaboration & Shared Ownership | 2. Explain the methods used to manifest meaningful collaboration and shared ownership           |
|                |                                                 | 3. Purpose of the process: How was the overall aim presented?                                   |
|                | c. Procedure Components & Methods               | 4. Describe rules of participation                                                              |
|                |                                                 | 5. How was the purpose of each meeting presented?                                               |
|                |                                                 | 6. In which areas did the co-creators require upskilling?                                       |
|                |                                                 | 7. What previous evidence was reviewed, and how?                                                |
|                |                                                 | 8. If a prototype or pilot was developed, describe the prototype and the prototyping process    |
|                |                                                 | 9. Give examples of interactive techniques or methods used                                      |
|                |                                                 | 10. Give examples of how iteration occurred during the process                                  |
|                |                                                 |                                                                                                 |
| 3. Evaluation  | a. Process                                      | 1. Explain how co-creator satisfaction and contribution evaluated.                              |
|                |                                                 | 2. How are results reported back to stakeholders and the public?                                |
|                |                                                 | 3. Explain how the validity of the process was evaluated                                        |
|                | b. Outcome                                      | 4. Explain how the validity of the outcome was evaluated                                        |
|                |                                                 | 5. Explain plans for formal testing of the effectiveness/ scalability of the co-created outcome |

**Table 2***Overview of Co-Design Meetings*

|           | Discussion Topics                                                                                                                                                                                                                                                                                                                                             |
|-----------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Meeting 1 | <ul style="list-style-type: none"> <li>• Meet &amp; greet</li> <li>• Overview and purpose of the project</li> <li>• Introduction to CBPR and co-design principles</li> <li>• Discussion of team roles</li> <li>• Overview of video formats and creative process by the creative team</li> </ul>                                                               |
| Meeting 2 | <ul style="list-style-type: none"> <li>• Decision-making during conflicts using voting</li> <li>• Selection of project name: HOPE</li> <li>• Decision regarding video format</li> <li>• Discussion of language, framing of the video, and target audience</li> </ul>                                                                                          |
| Meeting 3 | <ul style="list-style-type: none"> <li>• Discussion of call to action and resources to include at the end of the intervention</li> <li>• Research presentation on the stigma model and how moderators influence it</li> <li>• Older adults expressed interest in appearing in the video intervention</li> </ul>                                               |
| Meeting 4 | <ul style="list-style-type: none"> <li>• Discussion of video tone and overall approach</li> <li>• Further discussion of intervention content</li> <li>• Identification of intended outcomes of the intervention</li> <li>• Discussed research on the content and approaches used in existing interventions</li> <li>• Scheduling of pre-interviews</li> </ul> |
| Meeting 5 | <ul style="list-style-type: none"> <li>• Review and feedback on initial storyline developed by the creative team based on prior discussions and pre-interviews</li> </ul>                                                                                                                                                                                     |
| Meeting 6 | <ul style="list-style-type: none"> <li>• Review and feedback on the first draft of the video</li> <li>• Discussion of older adults' experiences with filming</li> <li>• Team ideas for animations to enhance the video</li> </ul>                                                                                                                             |
| Meeting 7 | <ul style="list-style-type: none"> <li>• Feedback on the first draft of the video</li> <li>• Finalizing animation elements</li> <li>• Feedback on Canadian Psychological Association (CPA) presentation</li> <li>• Feedback on call-to-action resources</li> <li>• Invitation to be involved in future research stages</li> </ul>                             |
| Meeting 8 | <ul style="list-style-type: none"> <li>• Screen final video intervention</li> <li>• Thanking all team members</li> <li>• Celebration</li> </ul>                                                                                                                                                                                                               |

**Table 3***PEET-6 Scores for All Meetings, Reported as Mean (Range)*

| PEET-6 Items                                                                                                                                              | Meeting 1  | Meeting 2  | Meeting 3  | Meeting 4  | Meeting 5  | Meeting 6  | Meeting 7  |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------|------------|------------|------------|------------|------------|------------|------------|
| 1. To what extent do you believe that your ideas were heard during the team meeting?                                                                      | 6.22 (3-7) | 6.86 (6-7) | 6.75 (6-7) | 6.50 (6-7) | 6.78 (6-7) | 6.75 (6-7) | 6.75 (6-7) |
| 2. To what extent do you believe organizers took your contributions at today's team meeting seriously?                                                    | 6.11(3-7)  | 6.86 (6-7) | 6.75 (6-7) | 6.63 (6-7) | 6.78 (6-7) | 6.63 (6-7) | 6.63 (6-7) |
| 3. To what extent do you believe that your input will influence final decisions the team makes about the video intervention?                              | 6.00 (4-7) | 6.43 (5-7) | 6.13 (5-7) | 6.00 (5-7) | 6.22 (5-7) | 6.38 (5-7) | 6.38 (5-7) |
| 4. To what extent were you able to clearly express your viewpoints?                                                                                       | 5.75 (3-7) | 6.43 (4-7) | 6.38 (5-7) | 6.38 (6-7) | 6.67 (6-7) | 6.43 (5-7) | 6.43 (5-7) |
| 5. To what extent did all participants have equal opportunity to participate in discussions?                                                              | 5.88 (4-7) | 6.57 (4-7) | 6.63 (5-7) | 6.63 (6-7) | 6.44 (5-7) | 6.86 (6-7) | 6.86 (6-7) |
| 6. To what extent was information made available to you either prior to or during the team meeting so you could participate knowledgeable in the process? | 6.57 (5-7) | 6.14 (3-7) | 6.75 (6-7) | 6.38 (5-7) | 6.78 (6-7) | 6.71 (6-7) | 6.71 (6-7) |

**Table 4***Attendance Record: Number of Co-Design Team Members Present at Each Meeting*

|           | Core Research<br>Team | Older Adults | Video Design<br>Experts | Total |
|-----------|-----------------------|--------------|-------------------------|-------|
| Meeting 1 | 4                     | 5            | 2                       | 11    |
| Meeting 2 | 2                     | 5            | 1                       | 8     |
| Meeting 3 | 3                     | 5            | 2                       | 10    |
| Meeting 4 | 4                     | 5            | 0                       | 9     |
| Meeting 5 | 4                     | 5            | 2                       | 11    |
| Meeting 6 | 4                     | 5            | 2*                      | 11    |
| Meeting 7 | 3                     | 5            | 2                       | 10    |
| Meeting 8 | 4                     | 5            | 1                       | 10    |

*Note.* \*One of the video design team members was an animator in this meeting.

**Table 5***Key Recommendations for Facilitating Co-Design Processes*

| Domain          | Subdomains                  | Recommendations                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
|-----------------|-----------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| I. General      | 1. Research meetings        | i. Schedule additional meetings with the research team between co-design meetings to discuss any challenges and potential biases transparently                                                                                                                                                                                                                                                                                                                       |
| II. Planning    | 2. Recruitment              | i. Recruit a manageable number of people<br>ii. Pre-interviews to understand potential participants' motivations for the project, and their comfort in sharing their opinions in a group setting<br>iii. Recruit diverse co-design participants who reflect the target population                                                                                                                                                                                    |
|                 | 3. Team building            | i. After recruitment, either hold a dedicated introductory meeting or devote a substantial portion of the first meeting to allowing team members to get to know one another before beginning the co-design process                                                                                                                                                                                                                                                   |
| III. Conducting | 4. Facilitate participation | i. Choose the location and timing for each meeting collectively as a team<br>ii. Support team members in addressing scheduling and participation barriers to facilitate attendance at the meeting<br>iii. Debrief team members who miss meetings<br>iv. Ensure that all team members have opportunities to contribute, especially those who are more reluctant to speak<br>v. Provide participants with research and other related material and resources in advance |
|                 | 5. Power dynamics           | i. Emphasize the unique value of each team members' expertise to the project<br>ii. Document team dynamics using field notes and reflexive journals, and review them before each meeting to prevent previously identified unhelpful dynamics from recurring                                                                                                                                                                                                          |

|                |                                                |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
|----------------|------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                |                                                | <ul style="list-style-type: none"> <li>iii. Check-in with non-academic team members after each meeting to assess whether they felt heard and valued, and to gather feedback to improve subsequent meetings</li> <li>iv. Pay attention to seating arrangements so that research and community members are mixed rather than sitting together inadvertently reinforcing power differentials</li> <li>v. When power imbalances arise, intentionally create space for all team members to contribute by inviting quieter members to share their perspectives without placing undue pressure on them</li> <li>vi. Establish shared decision-making strategies at the outset of the project, such as discussion and voting, to manage disagreements, resolve conflicts, and reach consensus</li> </ul> |
|                | 6. Relationship building                       | <ul style="list-style-type: none"> <li>i. Allow time for casual conversation among team members by scheduling breaks during meetings and providing food and beverages</li> </ul>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
|                | 7. Integration of different forms of knowledge | <ul style="list-style-type: none"> <li>i. Researchers should continually strive to integrate different forms of knowledge to ensure that the final product reflects the expertise of all team members</li> <li>ii. Make research concepts tangible and accessible for non-research team members</li> <li>iii. Avoid technical jargon, or explain it in lay terms when its use is necessary</li> <li>iv. Provide a brief summary of the previous meeting at the beginning of each meeting to ensure team members are on track</li> </ul>                                                                                                                                                                                                                                                          |
| IV. Evaluation | 8. Process evaluation                          | <ul style="list-style-type: none"> <li>i. Use brief standardized measures at the end of each meeting to provide all team members with an opportunity to provide anonymous feedback</li> <li>ii. Share the results of these measures at the following meeting to provide the team with data on the degree to which co-design is working and to facilitate</li> </ul>                                                                                                                                                                                                                                                                                                                                                                                                                              |

|                               |                         |      |                                                                                                                                                                                                                     |
|-------------------------------|-------------------------|------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                               |                         |      | conversation about ways to address aspects of co-design that are not working                                                                                                                                        |
|                               |                         |      | iii. At the end of the process conduct exit interviews to gather a deeper understanding of team members' experiences with the co-design process                                                                     |
| V. Researcher Characteristics | 9. Interpersonal skills | i.   | Warm, friendly, respectful, engaging and receptive                                                                                                                                                                  |
|                               | 10. Attitudes           | i.   | Motivated and committed to the principles of co-design                                                                                                                                                              |
|                               |                         | ii.  | Trust in the expertise of other team members                                                                                                                                                                        |
|                               |                         | iii. | Respect plurality of knowledge                                                                                                                                                                                      |
|                               |                         | iv.  | Flexible and adaptive                                                                                                                                                                                               |
|                               | 11. Positionality       | i.   | Continually reflect on power and privilege not only as a member of the research team but also in relation to one's intersecting social identities, lived experiences and position in society throughout the process |
|                               |                         | ii.  | Consider how these factors may emerge during meetings and shape researchers' ability to relate to others in the room                                                                                                |

## Appendix

### Meeting Agendas

#### Meeting 1 (October 08, 2025)

1. Welcome & Informed Consent (~5 mins)
2. Overview of project (~10 mins)
  - Stigma of seeking help is a problem
  - Long-term goal: develop a video
  - How we will get there
3. Overview of community-based participatory research (CBPR) (~5 mins)
  - Discussion of team roles
4. Icebreaker/Introductions (~15 mins)
  - 1-2 minutes to share with the group:
  - What expertise you bring with you
  - Why this project is important to you
5. Refreshment break & mingling (~15 mins)
6. Tripwire presentation & discussion (~20 mins)
7. Scheduling next meeting(s) (~5 mins)
8. Homework (~5 mins)
  - Which video format do you like?
  - Let's choose a team name
9. PEET Survey (~5 mins)

**Meeting 2 (Nov 19, 2025)**

1. Sign oath of confidentiality (~2 mins)
2. Review of PEET results and first meeting (any thoughts or concerns) (~15 minutes)
3. Description of how we will be making decisions (~3 mins)
4. Review last meeting's homework assignment (large group ~30 mins)
  - Feedback on team name
  - Preferred video format
    - Option 1, 2, or 3
    - If we want older adults' voices:
      - Recruitment
      - How many stories do we want - One story? Multiple stories?
5. Break (~10 mins)
6. Show example mental health intervention videos and a brief discussion (~10 mins)
7. Chat about frame/narrative of the video (~15 mins)
8. Homework assignment and PEET survey (~5 mins)
  - Prepare a little bit about journeys and stories in navigating the mental health system, asking for help, etc.

**Meeting 3 (December 10, 2025)**

1. Review of PEET results (~2 mins)
2. Review homework assignment (~15 mins)
  - WHO is our target audience?
  - WHAT does the audience desire?
  - WHAT is the goal? i.e. What would we like the audience to do after seeing this video?
3. Discussions about: (a) whose stories to include in the video, and (b) how many stories we want to include (~10 mins small groups, ~15 mins large group)
4. Break (~10 mins)
5. Targeting mental health literacy (MHL), perceived control (PC), and self-stigma (SS) in our video (~35 mins)
  - AR shares Vogel's theoretical model & work from our lab
  - Discussion of personal experiences with MHL, PC, and SS in relation to mental health journeys
6. Homework assignment and PEET survey (~5 mins)
  - Prepare to share journeys and stories in navigating the mental health system, asking for help, etc. (including how MHL, PC, and SS were involved)
  - Instructions from XX about things she wants us to provide

**Meeting 4 (January 07, 2026)**

1. Review of PEET results (~2 mins)
2. Recap and consolidation of our progress so far (25 mins)
  - Identify any gaps or missed perspectives
3. Revisit our discussion from last meeting on mental health literacy, perceived control, and self-stigma (10-15 mins)
4. Break (~10 mins)
5. Brief overview and discussion of the literature on social contact and stigma (10 mins)
6. Brief discussion on dissemination of research (~5 mins)
7. Homework assignment and PEET survey (~5 mins)
  - Write a reflection (e.g. your perspectives, thoughts, and experiences) on the co-design process so far, to revisit during the final interview.
    - Can be any format: point-form, a paragraph, a page, etc.
  - Prepare for interviews with Video design team
8. Schedule a new time for future meetings (~5 minutes)

**Meeting 5 (February 04, 2026)**

1. Review of PEET results and gather reflection papers (~2 mins)
2. Sign video consent forms (~2 mins)
3. Experience with pre-interviews (~8 minutes)
4. Colin & Jess share timeline and story arc (30 mins)
5. Break (~10 mins)
6. Discuss preliminary thoughts on story arc and final interview questions(20 mins)
7. Discuss dissemination of results (~5 mins)
  - Centre on Aging symposium
8. Reschedule March 4<sup>th</sup> meeting (~10 mins)
  - March 18<sup>th</sup>
9. Homework assignment and PEET survey (~5 mins)
  - Final interviews

**Meeting 6 (April 10, 2026)**

1. Review of PEET surveys and gather reflection papers (~2 minutes)
2. Review of the first draft of the video (~50 minutes)
  - Feedback
3. Finalization of animation components
4. Break (~10 minutes)
5. Next Meeting (~10 minutes)
6. Discussion of Gala event (location, panel, and format)
7. Discussion about the agenda for next meeting
8. Planning for end-of-project semi-structured interviews (~10 minutes)
9. Schedule our final meeting (~5 minutes)
10. PEET surveys (~2 minutes)

**Meeting 7 (May 22, 2026)**

1. Review of PEET results (~2 minutes)
2. Video Animation and Call to Action Resources discussion (~ 35 minutes)
3. CPA Presentation for Feedback (~10 minutes)
4. Break (~10 minutes)
5. Invitation for Next Steps – Consent Form Discussion (~10 minutes)
  - Jagpreet's defense
  - Final HOPE meeting
  - Gala event
  - Semi-structured interviews
  - Randomized controlled trial
6. PEET-6 Surveys (~2 minutes)
7. Photographs (~ 6 minutes)
8. Scheduling HOPE Final Meeting (~ 5 minutes)