

RESEARCH ARTICLE

Practical social media recommendations for dementia prevention researchers

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Funding information

Alzheimer's Association Research, Grant/Award Number: AARG-20-677396; AGE-WELL Networks of Centres of Excellence program, Grant/Award Number: AW-HQP2022-03; Canadian Consortium on Neurodegeneration in Aging; University of British Columbia Four Year Doctoral Fellowship; National Institute on Aging; National Institutes of Health, Grant/Award Number: R24AG063718

Abstract

INTRODUCTION: Practical social media recommendations are needed to facilitate greater engagement in dementia prevention research. Alongside relevant experts, our aim was to develop a set of consensus recommendations that reflect the values and priorities of prospective participants to guide social media use.

METHODS: We conducted a three-round, modified Delphi consisting of three online surveys and three conferences calls. The diverse, international Delphi panel comprised 16 experts with lived ($n = 10$) and professional ($n = 6$) experiences. Consensus was defined a priori as $\geq 70\%$ agreement.

RESULTS: Twenty-six items achieved consensus. Two items reached consensus in round 1: ethical considerations of closed social media groups (88%) and of social media users sharing prevention content with connections who are not on social media (79%). Nine items reached consensus in round 2, related to misinformation (79%), stigma (93%), and other key aspects of social media communication. After revisions, 15 items reached consensus in the final round. These items included: identifying when researchers ought to engage, managing closed social media groups, rankings of short form content, prioritizing lay summaries and multimedia resources, and rankings of preferred language. One item about the language of prevention for audiences living with dementia did not reach consensus. Final consensus items formed the new set of recommendations, which we organized into seven social media use cases. These use cases include setting up a social media page or community, handling online misinformation, actively challenging stigma, handling difficult online interactions, introducing new research to the public, help with study recruitment, and the language of prevention when writing posts.

DISCUSSION: These consensus recommendations can help dementia prevention researchers harness social media use for the purposes of public engagement and uphold the norms and values specific to the dementia research and broader communities.

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KEYWORDS

consensus, Delphi, dementia, ethics, prevention, recruitment, social media

Highlights

- We created social media recommendations with research and community experts.
- Recommendations cover key ethical considerations for dementia prevention research.
- Areas include misinformation, stigma, information updates, and preferred language.
- Full consensus recommendations are organized into seven social media use cases.

1 | BACKGROUND

The participation of individuals without cognitive impairment in research is critical for the advancement of interventions to delay or prevent the onset of dementia, including multidomain trials of lifestyle factors, biomarker innovation, and disease-modifying therapies.¹⁻⁴ Social media is being explored as a tool to address disparities in dementia research^{5,6} and drive participation in prevention studies and brain health registries.⁷⁻⁹ However, dementia-related stigma, predatory practices, misinformation, and other ethical considerations influence user engagement with prevention research content on social media.¹⁰ Both within and outside the dementia prevention context, researchers and ethicists report insufficient social media guidance that address key ethical considerations.^{10,11}

This normative gap comes with an important opportunity cost. Social media can be useful for presenting and interacting with prevention content, which targets a younger aging population. Audiences of dementia prevention research content include young to older adults, and experiences of different states of health, risk, familiarity with dementia, and digital literacy. While clinical settings act as established avenues for recruitment, they present barriers to enrolling participants without cognitive impairment.¹²⁻¹⁴ Asymptomatic individuals are less likely to seek dementia resources and may not be aware of their eligibility in prevention studies. Related factors also influence the involvement of cognitively unimpaired and marginalized populations such as attitudes toward research participation,¹⁵⁻¹⁷ perceived risk of dementia, a family history of dementia,¹⁸ and inequitable eligibility criteria.¹⁹ Calls to reform the conceptual framework underpinning dementia prevention research highlight the value of sustained media engagement to facilitate education and outreach.¹³ The onset of the COVID-19 pandemic accompanied a rise in technological uptake²⁰ and social media use by older adults.²¹ Thus, social media is increasingly well suited to work in parallel with in-clinic approaches to distribute culturally appropriate prevention research content to both younger and older aging populations.

From a dementia prevention research lens, we define social media engagement as a social and relational exchange between research professionals and community members with lived experiences.^{10,22} There

are some useful recommendations on the ethical use of social media in health research (e.g., Darko et al.,²³ Gelinas et al.,²⁴ Bender et al.,²⁵ Arigo et al.,²⁶ Goldman et al.,²⁷ Bhatia-Lin et al.,²⁸ and Zimmerman et al.²⁹), with most focusing on recruitment, retention, and tracking. Outside of recruitment, examples of social media engagement include the sharing of knowledge, personal experiences, opportunities, and advocacy efforts.^{30,31} There is very limited investigation specific to the intersection of dementia prevention and the ethical considerations of social media engagement.^{10,32}

The aim of this study builds on prior analyses of social media data. Dementia prevention research is a major topic on popular social media sites,³⁰ and dementia researchers interested in using these platforms report a need for more contextually relevant ethical guidance.¹⁰ Integrating the perspectives of researchers and people with lived experiences, we used a modified Delphi process to create practical ethical recommendations for dementia prevention researchers using social media for various forms of public engagement. By focusing on a specific health context, we hoped to prioritize relevant ethical criteria and encourage more consistent ethical decision making in research.

2 | METHODS

2.1 | Study design

Between May and August 2023, we sought expert consensus via an online, modified three-round Delphi. Each Delphi round included: (1) an online, anonymous questionnaire; (2) a Zoom conference call to discuss findings, resolve issues, and organize the next round. Panelists answered questions aiming to define ethical issues and generate solutions regarding social media use for research-public engagement in dementia prevention research. The Delphi is ideal for our research objective, which is highly context- and expertise-specific and benefits from the co-construction of knowledge by experts with professional and lived experiences. Reporting follows guidance on Conducting and Reporting Delphi Studies (CREDES).³³ The study received ethics approval at the University of British Columbia (H20-00530).

2.2 | Definition of consensus

We defined consensus a priori to be $\geq 70\%$ agreement (or negative agreement) among respondents for each statement.³⁴ For ranked items, a minimum of one option ranked in the top (or bottom) three was needed to reach $\geq 70\%$ agreement. Items evaluated on a 4-point Likert scale ranged from: “disagree,” “mostly disagree,” “mostly agree,” and “agree.” Items reaching the agreement threshold but requiring adjustment based on panelist feedback received the label “preliminary consensus” and were retained for the next round. We discussed items with no consensus or comments that appeared to conflict on conference calls. If no consensus for an item occurred after the third round, we accepted this as non-consensus or dissensus.

2.3 | Expert panel

Eligible participants were English-speaking adults available to complete three Delphi rounds. Living with advanced cognitive impairment was an exclusion criterion. Recruitment used the same multimodal methods as in earlier phases of this work,¹⁰ such as online databases, digital newsletters, professional networks, and the Collaborative Approach for Asian Americans & Pacific Islanders Research & Education (CARE) Registry. Panelists received a \$400 CAD honorarium for participating.

The international panel consisted of 6 professional experts working in dementia research (e.g., researchers, coordinators) and 10 experts by experience. Professional experts held expertise in health services; research ethics; research recruitment and retention; community outreach; engagement of diverse, at-risk populations; and science communication, among others. Experts by experience held expertise as caregivers or care partners, people with family and networks living with dementia, and individuals interested in dementia prevention. Some experts had both professional and lived experiences.

2.4 | Survey design

We developed round 1 survey items based on data collected in earlier project phases. Qualitative interviews with professional and lived experience experts revealed ethical factors influencing engagement such as diminished privacy, stigma, misinformation, and digital inequities.¹⁰ Panelist feedback drove the selection of survey items in subsequent rounds.

The surveys, delivered on Qualtrics, presented one item per page and the results from the previous round(s).³⁴ We provided quantitative results in percentages as the overall statistical group response, followed by qualitative, anonymized data. Between rounds, we summarized the group responses for each item. We made relevant updates to each item based on panelist comments in the surveys and the conference calls. The research team piloted the survey instruments for clarity and flow.

RESEARCH IN CONTEXT

1. **Systematic review:** This modified Delphi study is the final part of a three-phase project. In phase 1, we performed a content analysis of public Facebook and Twitter posts about dementia research to capture existing content exchange practices. In phase 2, we interviewed diverse experts to identify key ethical considerations regarding social media use in dementia prevention research.
2. **Interpretation:** With data and literature gathered from earlier phases, we co-created final consensus recommendations for dementia prevention researchers using social media in collaboration with professional and lived experience experts. Reporting follows Conducting and Reporting of Delphi Studies (CREDES) guidance.
3. **Future directions:** Implementation of these recommendations may facilitate research-public engagement on social media sites in the area of dementia prevention research. The recommendations highlight diverse areas of online interaction, of which investigation into different research contexts may reveal additional ethical considerations.

2.5 | Conference calls

Conference calls began with a verbal review of consent and a Zoom tutorial. Panelists used first names only and remained off camera to maintain a level of anonymity. Calls followed a structured discussion of survey items and remarks by panelists, prioritizing those items without consensus. To mitigate undue influence on the group discussions by dominant voices, we used careful Zoom facilitation with two moderators and offered multiple opportunities for comment from the panelists. We concluded each call with a summary of plans for the next round and invitations to provide feedback. After each call, all panelists received a summary of the discussion and a copy of the slides.

2.6 | Data synthesis and analysis

Positioned within a constructivist epistemology inherent to the quantitative and qualitative design of the Delphi,^{35,36} we evaluated panelist feedback to organize a set of social media recommendations for ethical practice in dementia prevention research. We closely followed panelist feedback to deliberate, remove/introduce, construct, and iterate each survey item with the goal of reaching consensus. After the Delphi, we shared the complete recommendations with the panelists for final evaluation and comments.

3 | RESULTS

3.1 | Rounds and participation

Survey responses per round were as follows: $n = 16$ (round 1), $n = 14$ (round 2), $n = 13$ (round 3). Two panelists withdrew after the first round. All panelists received invitations to all conference calls. Conference call attendance was as follows: $n = 12$ (round 1), $n = 13$ (round 2), $n = 6$ (round 3). Delphi participant characteristics are listed in Table 1. Figure 1 is a flowchart of all survey items.

3.2 | Delphi round 1

In the first round, panelists answered a combination of 21 open-ended and 10 multiple-choice questions related to:

1. Expectations of engagement (community guidelines, how to engage, responding)
2. Handling public dialogue (misinformation, stigma, public criticism, offense)
3. Crafting a social media post (audience, language of prevention)
4. Information updates (preferred format, presenting findings)
5. Study recruitment (privacy, participant rights, online/offline networks)

Panelists discussed ethical considerations related to dementia prevention research and provided recommendations which formed the foundation of the survey items presented in subsequent rounds. They expanded upon language use for dementia prevention for different audiences. Panelists favored responding to comments over not responding, especially to correct misinformation, explicitly challenge stigma, and engage in genuine instances of dialogue (including critiques) about dementia prevention research. They reported that open dialogue is more helpful for combatting stigma and supports public education. Being too busy was not considered a good reason to end a conversation/not respond.

Panelists favored transparency-enhancing actions. They preferred that dementia researchers explicitly address changes in evidence or information, as opposed to deleting old or outdated posts without comment. For example, acknowledging outdated recommendations shows a journey of changes and illustrates the scientific process. Panelists supported fostering trust in science by making it accessible and comprehensible. They also expressed strong support for spreading awareness of research participant rights on social media, believing it would be beneficial for recruitment.

Two items with implications for online privacy reached consensus. Panelists ($n = 16$) agreed that it is ethically appropriate for dementia researchers to create closed social media groups for long-term study engagement (88%) and to recruit individuals without social media through their networks who do use social media (79%). Four

TABLE 1 Demographics of Delphi expert panel participants.

	n (Total = 16)	%
Age^a		
18–30	5	31.3
31–40	4	25.0
41–50	2	12.5
51–60	1	6.3
61–70	2	12.5
>70	2	12.5
Gender^a		
Gender-fluid	1	6.3
Man	3	18.8
Woman	11	68.8
Prefer not to say	1	6.2
Sexual orientation^a		
Bisexual	1	6.3
Heterosexual	15	93.8
Education^a		
High school degree or equivalent (e.g., GED)	1	6.3
Some college but no degree	1	6.3
Associate's degree	2	12.5
Bachelor's degree	4	25.0
Graduate degree	8	50.0
Total household income^a		
Less than \$25,000	2	12.5
\$25,000 to \$34,999	1	6.3
\$50,000 to \$74,999	2	12.5
\$100,000 to \$149,000	2	12.5
\$150,000 or more	5	31.3
Prefer not to say	4	25.0
Race and ethnicity^a		
East Asian, South Asian, Southeast Asian, or Asian American	5	31.3
Black, African American, African	1	6.3
White	7	43.8
Middle Eastern or North African	1	6.3
Multi-racial	2	12.5
Expert type^b		
Lived experience	10	62.5
Professional	6	37.5

^aOptions with no responses are excluded.

^bExperts with both professional and lived experiences could choose the category in which they preferred to identify themselves.

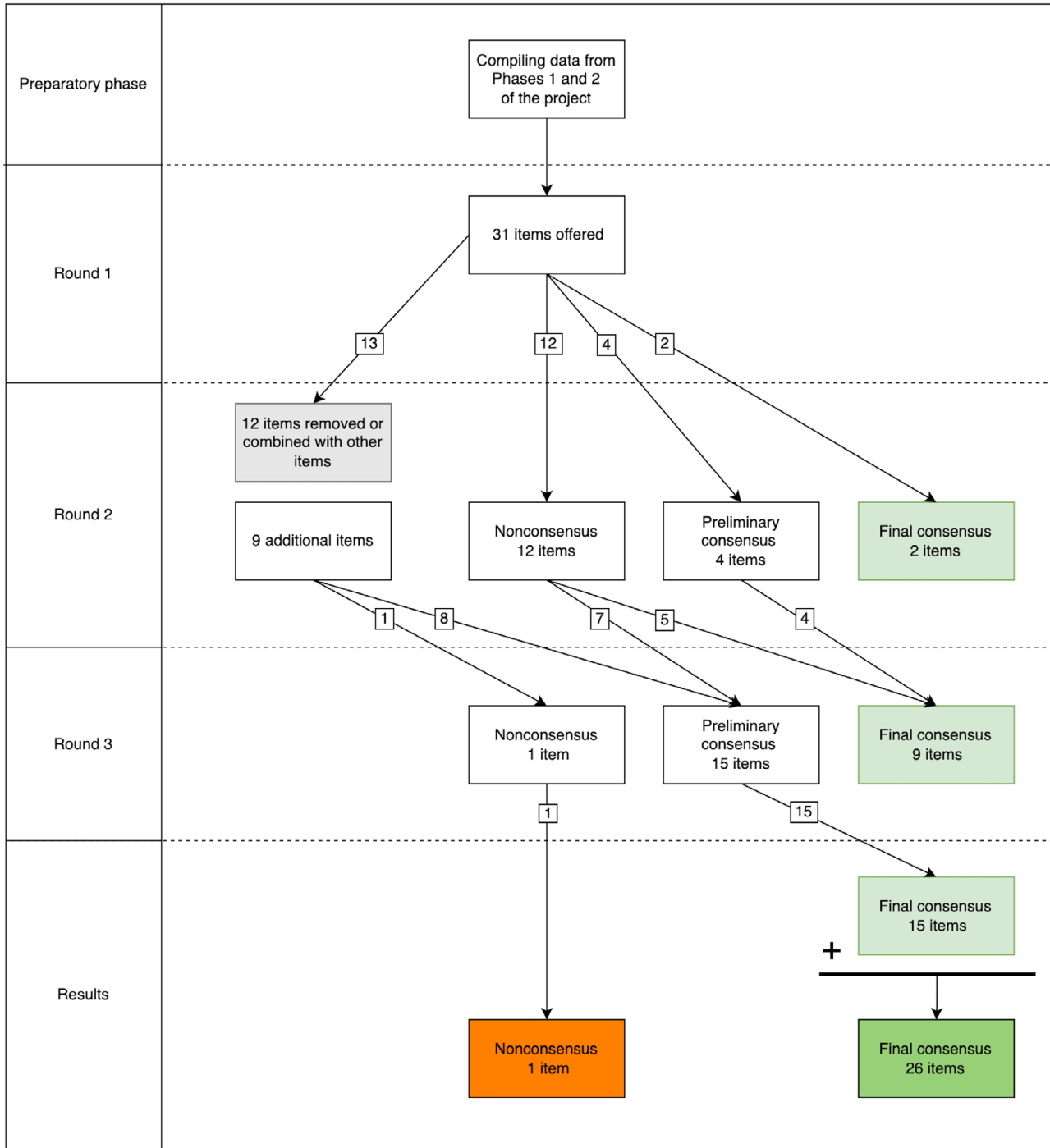


FIGURE 1 Flowchart of modified Delphi. Preliminary consensus defined as agreement $\geq 70\%$ but retained to check stability of consensus or to make minor adjustments to the survey item based on panelist feedback

items reached preliminary consensus. Table 2 illustrates the consensus ratings of survey items across all rounds.

3.3 | Delphi round 2

Due to overlapping or complementary recommendations, we removed or combined items with other items. Nine new items emerged from

panelist feedback in the previous round. One item aimed to refine a consensus definition of stigma. Most of the remaining additions specified language preferences for different audience types. We began survey item rankings in round 2 (Figure 2 and Table 3 display the final survey item rankings).

On prevention, panelists favored health-focused language for young and middle-aged adults. They described the term “healthy brain aging” as a positive term, emphasizing health and being proactive but still

TABLE 2 Consensus overview of non-ranked survey items.

Survey item	R1	R2	R3	Brief consensus descriptions
When to engage		79%	100%	Dementia researchers should engage in genuine, page-relevant interactions including requests for information or resources, dialectics, and misinformation.
When to disengage		86%		Dementia researchers can end an interaction on social media for disingenuous or bot comments, community guideline violations, content identified as not relevant, and when the conversation is no longer moving forward.
Define what comments not allowed		93%	100%	Dementia research pages should not allow comments that include disrespectful language, bot comments, conflicts of interest, content unrelated to dementia, spam, and stigmatizing or dismissive language about dementia.
General guidelines		93%	100%	General guidelines should provide information on the research organization, uphold facts, set expectations for engagement, define engagement boundaries, prioritize the latest prevention news, educate on patient-centered language, and uphold the guidelines.
Who should be in charge of social media communication	88%	100%		Responding to comments on social media pages should be done by: dementia researchers.
Who should be in charge of social media communication	75%	86%		Responding to comments on social media pages should be done by: communications specialists.
Defining misinformation	81%	93%		Misinformation occurs when people share wrong or false information about how to prevent dementia, or related content such as diagnosis, symptoms, experiences of people, prognosis and so forth. This can happen on social media. Misinformation includes statements that aren't based on the most recent scientific facts (i.e., rumors, guesses, outdated science information). Sharing false information could be intentional or unintentional. For example, people may unintentionally share false information through personal stories or anecdotal points. Misinformation may be more harmful if it is believed by large groups of people or shared by individuals identifying as experts. This is because people are more likely to be exposed to misinformation or believe it is true. Regardless of intent, if people believe misinformation over scientific evidence, it could be harmful for their health and well-being, the well-being of those in their care, and for public health.
How to handle misinformation		79%		Misinformation should be explicitly identified as such, responded to, corrected with links to sources, and be limited in its spread as much as possible.
Defining stigma		85%	92%	Stigma occurs when people face negative public attitudes, assumptions, or discriminatory behavior based solely on their connection to dementia. Ignorance about dementia contributes to stigma. Stigma may be directed toward people living with dementia, care partners, or their connected networks (i.e., friends, family). Outside social stigma, people may experience self-stigma, where they internalize stigmatizing beliefs and attitudes. People seeking dementia prevention or related resources are also affected. On dementia prevention, stigma may relate to beliefs about a person's future risk of dementia due to a family history or because they have additional risk factors that are also stigmatized (e.g., obesity). Some people may refrain from interacting with dementia-related posts on social media to avoid experiencing stigma.
Mitigate stigma to support public health	88%	93%		On social media, stigma-reducing measures should include responding to instances of stigma, explicitly identifying stigma, providing an explanation and links to resources, and making the response more visible than the stigmatizing comment.
Handle public communication—accidental offense		79%	92%	Posts that cause accidental offense should be considered for deletion and accompany a transparent statement of accountability.
Handle public communication—criticism		71%		Dementia researchers should respond to constructive public criticism by acknowledging it, providing a reasonable explanation, and indicate any improvements. Unhelpful criticism or misinformation should be handled differently.
Handle information updates when old information still exists on platform		86%		When sharing new evidence that contradicts information in older social media posts, the discrepancy should be acknowledged; old posts and new posts can be linked to each other to ease the information update.
Creating closed social media groups	88%			It is ethically appropriate for researchers to create closed social media groups to stay engaged with participants in long-term studies in a centralized online space.
Creating closed social media groups		93%	100%	Closed social media groups should account for the interest of participants, be optional, communicate privacy risks, have an early transition plan for study completion.

(Continues)

TABLE 2 (Continued)

Survey item	R1	R2	R3	Brief consensus descriptions
Determine ethical acceptance of recruiting individuals not on social media through social media	79%			It is ethically acceptable to recruit non-social media users through their networks who are active on social media.
Relevance of research participant rights on social media		93%		Researchers can increase awareness of participant rights by publicizing them as part of the recruitment plan, sharing a variety of multimedia, digestible resources dedicated to common questions and concerns, leveraging tech such as chatbots, and including sample stories.

Note: Preliminary consensus (*italics*). Consensus (no italics). Survey responses per round: R1 (n = 16); R2 (n = 14); R3 (n = 13).

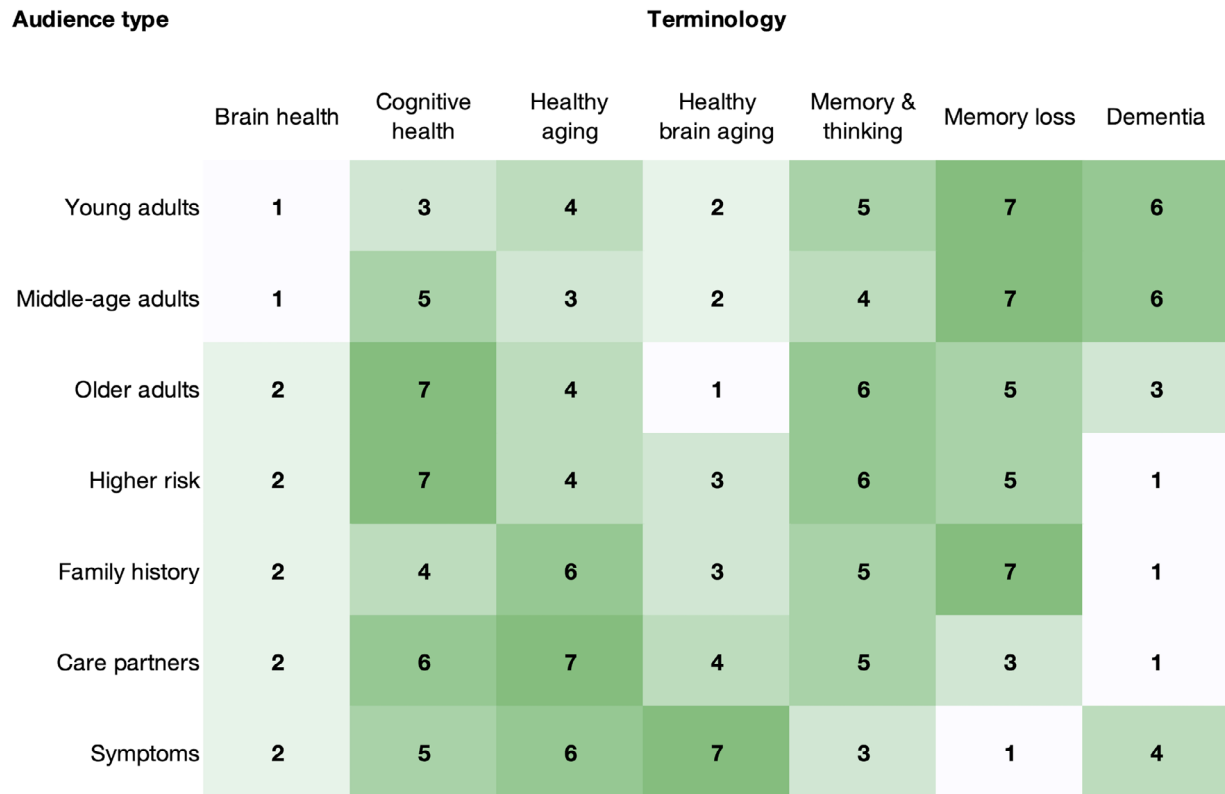


FIGURE 2 Heat map of final language rankings by audience type (1 = top rank, 7 = bottom rank). See Supplementary Materials for the comprehensive table of survey item rankings

implying age-related cognitive changes. In comparison, they reported “brain health” as sounding more static, and “healthy aging” as relatively broad (involving other body systems). Overall, they preferred positive language use. Panelists noted that some older adults may believe preventative efforts are no longer useful for them, even if this is not the case.

Nine items reached consensus (Table 2). Panelists agreed on actions for handling misinformation (79%), stigma (93%), public criticism (71%), introducing new information (86%), publicizing participant rights (93%), and appropriate conditions to disengage from social media interactions (86%). They agreed that dementia researchers (100%) and communication specialists (86%) should lead social media communication, but that graduate students, undergraduate students,

and other team members could assist with appropriate training and guidance. Fourteen items reached preliminary consensus.

3.4 | Delphi round 3

Panelists agreed that for certain audiences (i.e., older adults, those at-risk, those with a family history, care partners) it would be appropriate to use either dementia-focused or health-focused language. The same was not true for individuals experiencing dementia-like symptoms without a diagnosis. For this group, panelists identified terms like “dementia” or “Alzheimer’s” as especially stigma inducing. One panelist with professional and lived experience suggested that stigma may be

TABLE 3 Final consensus priority rankings of survey items for study information shared on social media (1 = top rank, 10 = bottom rank).

Information type	Ranking	Survey item
Short form content on social media recruitment posts	1	Research question/area
	2	Who can take part in the study
	3	Action item or next steps for those interested
	4	Contact information of study team
	5	What participants must do (e.g., blood draw)
	6	Time commitment
	7	Compensation for time
	8	Impact of the research
	9	Benefits to individuals who participate
	10	Facts and figures about dementia
Dementia information sources shared on social media	1	Lay summaries of the latest research or resources designed for non-experts
	2	Multimedia resources created by the research team (i.e., videos, infographics)
	3	Links to trusted organizations (e.g., Alzheimer's Association, National Institutes of Health)
	4	Links to scientific papers, journal articles

Note: See supporting information for the comprehensive table of rankings.

TABLE 4 Summary of use cases for social media recommendations.

Use case	Areas of recommendations
I need help setting up a social media community or page	<ul style="list-style-type: none"> • General recommendations (organization information, boundaries of engagement) • Define comments that are not allowed • When to engage/disengage • Leading communication • Closed social media groups
I need a strategy for handling misinformation on social media	<ul style="list-style-type: none"> • Definition of misinformation • Steps to handle misinformation
I want to actively challenge stigma on social media	<ul style="list-style-type: none"> • Definition of stigma • Steps to challenge stigma
I need help with difficult online interactions	<ul style="list-style-type: none"> • Accidental offense • Public criticism
I need help introducing the latest research to the public	<ul style="list-style-type: none"> • Presenting new information • Preferred information formats
I need help with study recruitment	<ul style="list-style-type: none"> • Reaching non-social media users • Participant rights • Most essential recruitment information
I need help writing a social media post	<ul style="list-style-type: none"> • Preferred language for different audience types

Note: See supporting information for detailed use cases.

the reason why individuals with symptoms do not yet have a diagnosis. Thus, they may disengage from social media posts containing these terms rather than seeking information or support. The panel prioritized using broader terms such as “memory loss” or “brain health” for individuals experiencing symptoms. We organized consensus items into use cases with detailed recommendations; an overview of these use cases is in Table 4. The full, detailed set of recommendations are in Supplementary Materials S1 in supporting information.

The revised versions of 15/16 remaining items reached consensus (Tables 2 and 3, Figure 2). Panelists agreed on recommendations promoting safe and just online environments. Examples included not

allowing comments that may harm others or oneself (100%; e.g., hate speech, personal health information), and establishing general community guidelines (100%; e.g., encouraging positive dementia messaging, communicating how often page is monitored). When using closed social media groups for a study, panelists agreed (100%) that researchers ought to explain the privacy risks (higher chances of identification) and create a transition plan for the study closure to avoid a sudden loss of community support.

One item did not reach consensus: language for people living with dementia. Earlier rankings of this item were highly debated. For this reason, we converted this item to a qualitative, open-ended

question for the final round. Panelists suggested that prevention-related language may be inappropriate for individuals with an irreversible condition. The resulting discussion concluded that using direct terms like “dementia,” “Alzheimer’s” (i.e., condition specific), or phrases such as “managing dementia” are more appropriate.

3.5 | Thematic content not captured in consensus

Individual panelists brought up points relevant to communicating dementia prevention research on social media. One professional expert remarked that the word “cognitive” might not be easily understood and requires additional explanation if used. One lived experience expert suggested that addressing a person’s social circle (e.g., a loved one), rather than the individual themselves, might be more effective at mitigating stigma around the word “dementia.”

Panelists supported the co-development of social media posts with dementia community members. They raised that co-development could bring credibility through both expert and lived experience perspectives and emphasize the active process of research, discussion, and collaboration.

4 | DISCUSSION

Using a modified Delphi process, international panelists created recommendations for dementia prevention researchers to facilitate ethical social media use and encourage online engagement.

There was robust agreement among panelists on 26 items, of which 24 were recommendations, and 2 were definitions. The expert panel was highly responsive to the initial list of 31 items informed by earlier project phases; most items reached consensus in early rounds. We repeatedly situated items within a dementia prevention research context in the surveys and conference calls. This process allowed for the creation of specific, practical guidance aimed at minimizing inconsistent ethical judgements in research.

Our recommendations reflect panelists’ shared expectations for conducting social media engagement in dementia prevention research. There was widespread agreement that dementia researchers should err on the side of active engagement (e.g., challenge stigma, address misinformation, respond to criticism, illustrate the process of science). While acknowledging it is ethically defensible for dementia researchers to disengage from certain online interactions, panelists agreed that being too busy is not a satisfactory reason to not engage with community members. An appreciation of the practical constraints of resources limitations on the ethical ideals of public engagement are discussed in other dementia¹⁰ and public health social media research.³⁷ Panelists also encouraged researchers to uphold safe, just social media environments by avoiding additional access barriers and using transparent practices. This is evidenced by their recommendations to, for example: openly address privacy risks, to actively counter misinformation and stigma, and to make social media membership optional for study participation. Panelists pre-

ferred lay summaries and multimedia resources for research–public engagement, because these methods are more accessible than journal articles.

Finally, panelists prioritized terminology for different audiences that would maximize engagement of dementia prevention research. Our data suggest that for certain audiences, the term dementia is more likely to elicit self-stigma (i.e., people with symptoms of cognitive impairment without a diagnosis) or be seen as irrelevant (i.e., young adults). While these patterns are consistent with reported stigma in some minority and ethnic communities,^{38,39} there is evidence that brief exposure to dementia information can reduce stigma regardless of the use of the label dementia.³⁹ This implies that choosing terminology is most critical for initiating engagement with dementia-related content on social media. Our recommendations for language use can supplement recent nomenclature frameworks which currently do not specify terminological alternatives to “dementia.”³⁸

The social media recommendations offered here differ from others in their contextual specificity, practical steps, and consensus-based development with diverse experts. An ethical rationale accompanies all our recommendations to justify why the prescribed steps matter. For example, the use case “I want to actively challenge stigma on social media” outlines how to respond to stigmatizing comments. The steps include explaining why the statement is stigmatizing from a dementia perspective, sharing resources to support given reasons, and mitigating further harms. Rationales for these steps acknowledge that stigma is not always intentional and may be confounded with other online harms: “Individuals may not be aware that certain statements are stigmatizing” and “Stigma may be intertwined with misinformation.” Emphasizing an active approach is warranted given the presence of dementia stigma on social media^{40,41} and reports that oversimplified dementia prevention messaging can be misleading, accusatory, or lead to negative health outcomes for people living with dementia.⁴²

Outside stigma, our use cases address how to manage research–public communications that are helpful for recruitment and also other forms of social media engagement. Examples include setting transparent engagement expectations: notifying community members how often the page is monitored, and the types of posts that will receive a response.

4.1 | Comparison to other studies

Situating social media use within the dementia prevention research context allowed for the prompting of specific, practical recommendations, whereas other ethical frameworks with a broader health research scope or specific to other research areas^{23–26,29,43,44} achieve a different goal. For example, a non-exceptionalist methodology used by Gelinis et al.²⁴ would compare a social media recruitment case to its offline variant and evaluate the similarities/differences—highlighting respect for privacy and investigator transparency. This approach is highly useful for ethical cases containing a large overlap with traditional offline scenarios. However, the flexibility of the methodology leaves a wider margin of error for researchers to interpret and

extrapolate ethically salient aspects of a situation. Dementia researchers with different levels of ethics training are more likely to form judgments ranging in quality and depth of ethical reasoning.

Other guidance specializes in principled privacy-preservation measures²⁵ or the boundaries of human subjects research when accessing public social media posts (i.e., data mining).^{45,46} Approaches marked for practical use within general⁴⁷ and pediatric research⁴⁸ integrate more policy considerations (e.g., ethics board, terms of service) or acknowledge the high-level need for ethical management plans and content strategies, respectively. There are currently no other social media recommendations created with and for the needs of dementia research and the impacted community as outlined here.

4.2 | Limitations

We acknowledge the limitations of our study. Although our findings are representative of the views of individuals impacted by social media use in dementia prevention research, they are likely not comprehensive of all relevant ethical considerations. Methodological risks such as inadvertent unblinding on social media are not directly addressed. However, our social media recommendations can be used in conjunction with other existing recommendations²⁴ that already offer potential solutions for this and other known challenges.

Despite the diversity of the expert panel across numerous categories, there remained demographic groups in need of greater representation. This could bias our recommendations in various ways. While our results prioritize accessible materials, higher levels of education in our panel may neglect specific communication needs of individuals without post-secondary education. Trust in research and its variability across historically marginalized groups (e.g., racial/ethnic minorities) are not explicitly discussed, which has implications for building online communities and dialogue. The views of non-heteronormative groups are underrepresented. We did not ask for rural/urban location or disability-related information. The international panel composition also poses challenges for social media recommendations across regions and cultures. Our language and stigma recommendations are most clearly influenced by a panel from predominantly English-speaking and Western regions. Given the Delphi's focus on agreement, differences in value systems are not broadly addressed. Social media platform usage and research norms, rights, or regulations also vary across regions. Although our recommendations aim to uphold just social media environments in a dementia prevention research context, the breadth of our recommendations does not account for the full range of intersectional factors.

There is no firm standard panel size for the Delphi. Our panel size falls well within some recommended ranges from 10 to 18, and as wide as 12 to 315.^{49,50} Social media is constantly evolving and may call for future iterations of the proffered recommendations, which we consider to be a living document sensitive to the needs of researchers and the community. Changes to the recommendations in the future

may need to account for the rise in popularity of short-form video content, additional platform safeguards (e.g., anonymous posting, content moderation), and shifting online language use. Finally, while the aim of the present work was to minimize interpretation of broad social media guidance, it is apparent that ethical decision making will always include some level of interpretation.

5 | CONCLUSIONS

Social media engagement in dementia prevention research warrants a set of ethical recommendations that highlight the values and priorities identified by researchers and those with lived experiences of dementia. After a three-round modified Delphi, we created a set of recommendations that uphold active researcher engagement, just and safe online environments, and appropriate language use for diverse dementia prevention audiences. Next steps for this project will focus on the evaluation and the dissemination of the recommendations to appropriate knowledge users.

ACKNOWLEDGMENTS

The authors would like to extend a big thank you to all our panelists, without whom this work would not be possible. This study is generously supported by the Alzheimer's Association Research Grant program #AARG-20-677396 (J.M.R.); AGE-WELL NCE Inc., a member of the Networks of Centres of Excellence program #AW-HQP2022-03 (J.M.R., V.H.); the Canadian Consortium on Neurodegeneration in Aging (J.M.R.); and the University of British Columbia Four Year Doctoral Fellowship (V.H.). The project described was supported by the National Institute on Aging of the National Institutes of Health under Award Number R24AG063718 (CARE Registry). The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. The sponsors had no role in the design and conduct of the study; in the collection, analysis, and interpretation of data; in the preparation of the manuscript; or in the review or approval of the manuscript.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest. Author disclosures are available in the [supporting information](#).

CONSENT STATEMENT

All human subjects provided informed consent.

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How to cite this article: Hrinco V, Roy KT, Robillard JM. Practical social media recommendations for dementia prevention researchers. *Alzheimer's Dement*. 2024;10:e12496. <https://doi.org/10.1002/trc2.12496>