

# Ethical Considerations at the Intersection of Social Media and Dementia Prevention Research

V. Hrinco<sup>1</sup>, G. Zaleski<sup>1</sup>, J.M. Robillard<sup>1,2</sup>

1. Division of Neurology, Department of Medicine, University of British Columbia, Vancouver, BC, Canada; 2. BC Children's and Women's Hospital, Vancouver, BC, Canada

Corresponding Author: Julie M. Robillard, B402 Shaughnessy, 4480 Oak Street, Vancouver, BC V6H 3N1 Canada; 604.875-3923, Tel: 604.875-3697, [jrobilla@mail.ubc.ca](mailto:jrobilla@mail.ubc.ca)

## Abstract

**BACKGROUND:** Ethical social media use underpins effective online engagement for dementia prevention research. Existing social media guidelines are broad and lack empirical justification reflecting the values and priorities of the dementia community and the challenges specific to prevention research.

**OBJECTIVES:** By engaging professional and community experts, we sought to identify the ethical issues, motivators, and barriers pertaining to social media engagement for dementia prevention research.

**DESIGN:** Semi-structured, qualitative interviews conducted online.

**SETTING:** We recruited participants using a combination of accessible online databases, advertisements/posters through organizational newsletters and websites, social media, registries, and from our network of colleagues.

**PARTICIPANTS:** Professional experts working in dementia research (n=15; e.g., researchers, coordinators) and experts with lived experience (n=14). Experts were from Canada, the USA, the UK, and Chile.

**MEASUREMENTS:** Discussions were analyzed using thematic qualitative analysis methods.

**RESULTS:** Professional experts revealed a dearth of social media guidelines for prevention research, relying on informal sources to supplement ethics board approval. They sought methods of strategic communication for public dialogue (e.g., misinformation, criticism). Experts by experience appreciated the educational benefits of social media but raised risks such as diminished online privacy, dementia-related stigma, being targeted for predatory practices, and misinformation. Various digital inequities (e.g., age, socioeconomic status) dampen social media's reach to diverse publics. Participants acknowledged that younger aging populations have more digital fluency and may benefit more from social media research engagement.

**CONCLUSIONS:** Research professionals and community members identified ethical and contextual factors surrounding the use of social media for dementia prevention, and a need for more guidance. The next project phase will use these data to inform the co-creation of ethical guidelines for brain health research.

*Key words:* Dementia, ethics, social media, prevention, qualitative methods.

## Introduction

Over the past decade, growing calls to address the dementia research recruitment crisis (1) accompanied a paradigmatic shift towards prevention (2, 3). Social media is a potentially useful method for presenting prevention research opportunities to healthy (or prodromal) aging populations—especially outside a clinical setting. A recent overview of Facebook and Twitter content revealed an abundance of publicly available dementia research resources, many focused on prevention (4). However, numerous ethical concerns arise from social media engagement (5–7) interacting with challenges specific to dementia prevention research (8, 9). There is currently minimal ethical investigation bridging together these technological and social realities.

As dementia is now understood to develop over decades, research priorities are increasingly focused on early lifestyles factors (2) or pharmacological interventions (10) to stop or delay the disease progress in healthy individuals. Engaging healthy participants by its nature is a barrier for prevention research, as this population may not be aware that dementia is relevant to them (1). These individuals are unlikely seeking dementia treatment or resources in clinical settings, which are key channels for trial recruitment. Group-specific risk-benefit assessments may also affect the participation of healthy or ethnoracially diverse individuals in prevention research (11–13). Social media engagement may serve as a complementary approach to enable various types of research-public communication to facilitate awareness, knowledge exchange, and greater involvement in dementia prevention research.

Social media engagement is a form of communication whereby social networks are the technological means of mediation. In dementia prevention research, engagement is a social and relational exchange (14) between research professionals (i.e., researchers, coordinators, ethicists) and community members (i.e., people with lived experiences, care partners, advocates). Communication plays the essential role of creating and shaping engagement outcomes (14). Visible social media activity (e.g., likes, shares) represents the lowest level of engagement. Higher levels of engagement include

emotional and cognitive states (e.g., trust, interest) and a willingness to engage (e.g., civic participation) (15, 16). Social media engagement is similarly influenced by the group outcomes and social settings of its actors. For example, factors affecting social media access (the 'digital divide') include chronological age, education, other sociodemographic variables (10), and attitudes and beliefs regarding who can be a technology user (11). This sensitivity to context emphasizes the importance of adopting a disciplinary lens to understand social media engagement. As defined, social media engagement includes the various ways researchers and the public may communicate bidirectionally about study participation, knowledge dissemination, sharing resources, or other opportunities to learn about or be involved in dementia prevention research.

Expansion towards social media engagement has normative implications for the inclusion of public and participant meanings and values. Recruitment-focused outreach could be critically evaluated as a type of research engagement that traditionally centers institutional goals and perspectives, where recruitment serves as a means to an end (16). Emerging health research practices aim to address these power asymmetries and forms of social exclusion. In aging research, intersectional and justice-informed frameworks of engagement prioritize participant and community needs by first building relationships, then cultivating openness and readiness to research opportunities of which participation is a by-product (17). Similarly, paternalistic research ethics models in the dementia space are shifting towards patient and public involvement that is inclusive of lived experience (18). Research engagement is a value-laden practice. Using social media to co-create meaning through research-public relationships departs from utilitarian, research institution-driven conceptions of engagement.

Dementia prevention researchers using social media should consider the needs of potential participants, research partners, and members of the general public who may benefit, experience harm, or be excluded from engaging with this content. Social networks are spaces not originally designed for research purposes. Rather, researchers must navigate the existing architecture of these online platforms whose communication norms are co-created through intersubjective exchanges between individuals, communities, and organizations.

Although several social media guidelines for research exist (6, 19, 20, 20–22), none are ideally suited to the dementia context. As general guidelines, they are not tailored to the needs and values of any specific health research field (i.e., dementia) or impacted community. Authors of a social media privacy framework acknowledge the challenges of capturing differing norms, methodological approaches, and conventions across research disciplines and ethics boards (19). Most guidelines focus on patient recruitment or retention, excluding other types of research engagement on social media. Previous findings indicate that dementia research

content on Facebook and Twitter is predominantly intended for sharing knowledge (e.g., research findings, general information, study updates, resources), followed by research opportunities and experiences (4). This implies that focusing on research recruitment may no longer be sufficient for guiding social media practice in dementia research. It also remains unclear whether any social media frameworks to date are informed by the perspectives of participant or patient populations—individuals ultimately affected by ethical decisions in research. Overall, existing recommendations leave researchers with the burden of interpretation which risks inconsistent ethical judgements in research.

The purpose of this study is to investigate the ethical issues, motivators, and barriers of social media engagement for dementia prevention research from the perspectives of professional and community experts. We sought the views of diverse experts to avoid a research institution-driven conceptualization of social media engagement (16, 23). Following a previous investigation of dementia research content on social media (4), we posed two research questions:

RQ1: What are the ethical factors influencing social media engagement of dementia prevention research from the views of research professionals and community members?

RQ2: How can we understand social media engagement in the context of dementia prevention research from the views of research professionals and community members?

## Methods

### *Study design*

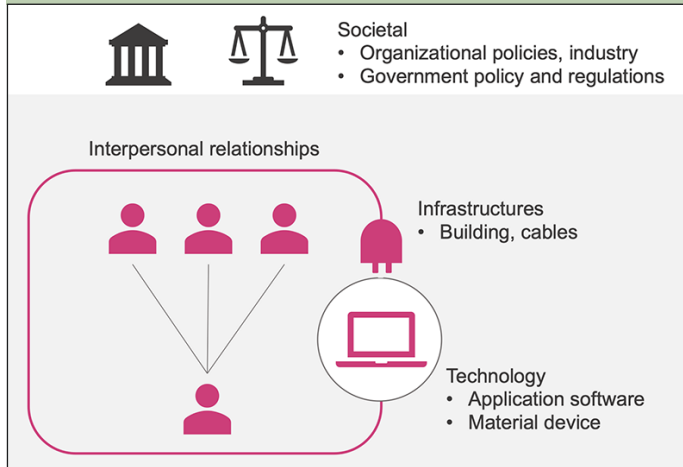
Between October 2021 and November 2022, we conducted semi-structured qualitative interviews with international experts in Canada, the United States (USA), the United Kingdom (UK), and Chile. Our goal was to identify the key ethical issues, motivators, barriers, and facilitators of social media use in dementia prevention research. Reporting follows the consolidated criteria for reporting qualitative research (24). This study received ethics approval at the University of British Columbia (H20-00530).

### *Conceptual framework*

We employed a sociotechnical ethical approach, which aims to highlight ethical considerations across distal but interconnected social domains (25). By drawing from a sociotechnical ethics approach (Figure 1), we broaden the ethical analysis outward from narrow understandings of what social media is technically and towards the social arrangements in which social media is used and constructed. This ethical analysis departs from conventional, universal approaches to identify

technological harms within the social, cultural, and political realities of the dementia prevention research context.

**Figure 1.** A sociotechnical ethics approach brings attention to the broader social world in which technologies are built and embedded (25)



### Study population

Participants composed two groups of experts: 1) professional experts working in dementia research (e.g., dementia researchers, ethicists, study coordinators) and 2) experts by experience (e.g., advocates, persons with lived experiences of dementia, caregivers, members of the public). Some participants could potentially fit in either group (e.g., caregivers employed as researchers). Eligible participants were adults, fluent in English, and able to meet over videoconference. One exclusion criterion was for individuals living with advanced cognitive impairment. To assess motivators and barriers, experience with social media was not required.

### Participant recruitment

We used purposive, convenience, and snowball sampling in a multi-modal strategy. Experts were recruited from freely accessible online databases, and we advertised through organizational newsletters and websites (e.g., AGE-WELL), Twitter, and from our network of colleagues. The Collaborative Approach for Asian Americans & Pacific Islanders Research & Education (CARE) Registry from the University of California San Francisco was another recruitment source for experts by experience. Recruitment halted when we reached thematic saturation (26, 27).

### Interview guide

We created two interview guides (one per group of experts) consisting of semi-structured questions that the research team pilot tested. Specific content varied according to the expert group. Vignettes were the same

for both groups. Interview questions fell under the following domains:

**Ethical elements:** 1) benefits/risks of social media engagement in dementia research, 2) resources to guide ethical use of social media for engagement (professionals).

**Motivators/barriers:** 1) past use of social media for dementia research, what worked or didn't work (professionals), 2) meanings and attitudes when using social media to learn about dementia research (experience).

**Dementia prevention-specific considerations:** context-specific factors (e.g., values, needs) related to dementia prevention research and social media use.

### Vignettes

The interviews included two social media vignettes for a situated exploration and discussion of ethical social media use in prevention research (28). To create the vignettes, we adapted real social media posts that invited participation in dementia risk reduction research. Both vignettes were Facebook recruitment posts for research trials.

### Interview procedures

Remote interviews held over Zoom began with an overview of the research aims and the informed consent process. Participants provided demographics prior to the interview questions. We designed the interviews to last 30 to 45 minutes. The first author (VH) facilitated the interviews and has training in qualitative research. Participants received a \$25 gift card as a token of gratitude.

### Analysis

We used qualitative thematic methods to guide the analysis (26). Interviews were audio-recorded, de-identified, and transcribed verbatim. Two coders (VH, GZ) performed multiple readings of the transcripts to become familiar with the data. Codebook creation followed an iterative process of inductive and deductive analysis. We added new codes based on their presence in the data or a priori codes informed by our research questions and previous literature, respectively. Using NVivo 12, we independently co-coded over fifteen percent of the transcripts until intercoder reliability exceeded 80%. We split the remaining transcripts between the coders. Coders took reflexive notes on codebook updates in a continuous audit trail. Weekly meetings covered discussions of preliminary themes, ambiguities, and disagreements. Major themes constituted recurrent, patterned experiences organized into concepts that described large portions of the data (26, 29). We contextualized the thematic narrative through an ethical lens (25) within the extant literature.

**Table 1.** Characteristics and social media use of all participants by expert type

	n (%)		
	Total (N = 29)	LE (N = 14)	P (N = 15)
<b>Age</b>			
18-30	6 (20.7)	4 (28.6)	2 (13.3)
31-40	6 (20.7)	0 (0.0)	6 (40.0)
41-50	7 (24.1)	2 (14.3)	5 (33.3)
51-60	2 (6.9)	1 (7.1)	1 (6.7)
61-70	5 (17.2)	4 (28.6)	1 (6.7)
>70	3 (10.3)	3 (21.4)	0 (0.0)
<b>Gender*</b>			
Man	8 (27.6)	4 (28.6)	4 (26.7)
Woman	20 (69.0)	9 (64.3)	11 (73.3)
I don't identify with any options provided	1 (3.4)	1 (7.1)	0 (0.0)
<b>Sexual Orientation*</b>			
Bisexual	1 (3.4)	0 (0.0)	1 (6.7)
Heterosexual	26 (89.7)	12 (85.7)	14 (93.3)
Prefer not to say	2 (6.9)	2 (14.3)	0 (0.0)
<b>Education*</b>			
High school degree or equivalent	1 (3.4)	1 (7.1)	
Some college, no degree	3 (10.3)	3 (21.4)	0 (0.0)
Bachelor's degree	6 (20.7)	5 (35.7)	1 (6.7)
Graduate degree	19 (65.5)	5 (35.7)	14 (93.3)
<b>Household Income*</b>			
<\$25,000	2 (6.9)	2 (14.3)	0 (0.0)
\$35,000 - \$49,999	5 (17.2)	5 (35.7)	0 (0.0)
\$50,000 - \$74,999	1 (3.4)	0 (0.0)	1 (6.7)
\$75,000 - \$99,999	2 (6.9)	1 (7.1)	1 (6.7)
\$100,000 - \$150,000	7 (24.1)	0 (0.0)	7 (46.7)
>\$150,000	9 (31.0)	3 (21.4)	6 (40.0)
No disclosure	3 (10.3)	3 (21.4)	0 (0.0)
<b>Race and Ethnicity*</b>			
East, South, or Southeast Asian, or Asian American	5 (17.2)	4 (28.6)	1 (6.7)
Black, African American, African	2 (6.9)	0 (0.0)	2 (13.3)
Hispanic, Latinx or Spanish	2 (6.9)	0 (0.0)	2 (13.3)
White	19 (65.5)	9 (64.3)	10 (66.7)
Multi-racial	1 (3.4)	1 (7.1)	0 (0.0)
<b>Region</b>			
U.S.A.	9 (31.0)	4 (28.6)	5 (33.3)
Canada	12 (41.4)	9 (64.3)	3 (20.0)
U.K.	7 (24.1)	1 (7.1)	6 (40.0)
Chile	1 (3.4)	0 (0.0)	1 (6.7)

**Table 1 (continued).** Characteristics and social media use of all participants by expert type

	n (%)		
	Total (N = 29)	LE (N = 14)	P (N = 15)
<b>Use of Social Media**</b>			
Non-user	5 (17.2)	2 (14.3)	3 (20.0)
Facebook	22 (75.9)	11 (78.6)	11 (73.3)
Twitter***	16 (55.2)	5 (35.7)	11 (73.3)
Instagram	8 (27.6)	7 (50.0)	1 (6.7)
YouTube	4 (13.8)	3 (21.4)	1 (6.7)
LinkedIn	5 (17.2)	1 (7.14)	4 (26.7)
TikTok	1 (3.4)	1 (7.14)	0 (0.0)
Snapchat	3 (10.3)	3 (21.4)	0 (0.0)
Reddit	2 (6.9)	2 (14.3)	0 (0.0)
<b>Opinion of Targeted Advertising</b>			
In Favour	9 (31.0)	4 (28.6)	5 (33.3)
Ambivalent	14 (48.3)	6 (42.9)	8 (53.3)
Not In Favour	6 (20.7)	4 (28.6)	2 (13.3)

LE= Experience; P= Professional; \* Options with no responses are excluded. See Appendix (A1) for the demographics collection sheet presented to participants.  
 \*\* Participants may use multiple platforms. Columns do not sum to the total number of participants. \*\*\* Data collected before the change in ownership of Twitter.

## Results

We recruited 15 professional experts working in dementia research and 14 experts by experience (Table 1). The mean interview length was 39 minutes. Five participants were not social media users.

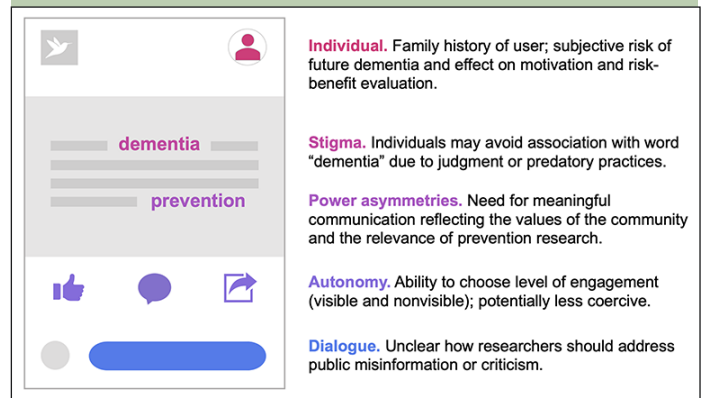
Our analysis revealed two overarching dimensions: 1) ethical elements and 2) technical elements. Ethical elements constituted 5 major themes: lack of ethical guidance, mutually beneficial goals, theoretical reach vs. actual accessibility, risk factors limiting engagement, and antecedent influences on engagement. Figure 2 summarizes key ethical factors.

### Ethical elements

#### Theme 1: Lack of ethical guidance

Professional experts acknowledged the lack of formalized ethical guidelines for social media engagement—not only for recruitment, but inclusive of various types of research-public communication. To supplement ethics committee review, professional experts referred to ethical principles (e.g., do no harm) or disparate, informal sources of appraisal such as partner organizations, other dementia or brain health researchers, colleagues, and friends.

**Figure 2.** Key ethical sub-themes relevant to dementia prevention research



The image depicts ethical features across broad domains of social media engagement beginning from the individual, post messaging as communication, interaction with the post, and direct dialogue.

One participant's response captured the need for contextually relevant guidance:

"I do not really think I have come across any particularly good guidelines. I would say it is generally completely lacking in everything. I think it is a question of how specific you should make the guidelines [...] we have probably very general ones in the U.K. of this is how you can use social media on research, but each patient group is going to have their own nuances [...] it would be helpful to have guidelines for ethics committees on how much they actually have to approve because it is not realistic to approve everything that is going to go on social media[...]" (005, professional).

Some participants expressed a specific need for guidance when managing social media dialogue. Examples included how to publicly respond to users sharing misinformation or harmful advice, addressing difficult questions, comments critiquing the study, online harassment, or the research team causing accidental offense. Study group participants' aim was to minimize harm to the public, the research study and team, and the academic institution.

Related concerns included who should be responsible for social media moderation and the need for dedicated resources to manage public dialogue. A research coordinator cited resource reallocation as the reason why they no longer have a dedicated communications officer for social media.

### *Theme 2: Mutually beneficial goals*

This theme describes how social media may be beneficial for both the goals of professional experts and to the goals of experts by experience, and ideally these goals will align. Most professional experts reported that social media could help generate broad interest in brain health research through spreading awareness, education, policy, and research findings. Other benefits included building an online presence to foster relationships with the community and partner organizations. One research coordinator summarized this view of social media use: "[...] it should just be about engaging people, raising awareness, and starting that connection, starting that relationship, making them aware of your project, and the possibility of taking part in it." (007, professional).

Experts by experience highly valued learning and accessing resources about dementia research on social media, especially for prevention. They expressed positive beliefs that education about dementia prevention could encourage health-seeking behavior, aid dementia research, and ultimately contribute to the common good.

Participants reported in various ways that prevention research content could still benefit users who minimally engage with social media. One participant captured how patterns of engagement are community-specific and irreducible to likes and shares:

"Asian communities tend to hide the negative [...] I have a lot of Asian family on Facebook [...] it would be helpful for me to share things so that they can see, and they can be educated, even if they do not have to share it themselves." (LE011, experience).

A dementia researcher explained that the ability to choose one's level of engagement on social media is empowering for agency and autonomy, and potentially less coercive than in-person interactions. Supporting that point, two experts by experience reported that they value viewing research posts to seek information without pressure to continue engaging.

### *Theme 3: Risk factors limiting engagement*

Participants explained how the risks of using social media for dementia research can negatively impact engagement.

Diminished privacy on social media was the main concern identified by experts by experience. Participants described feelings of reluctance or hesitancy to post on social media and wanted to avoid unauthorized data sharing by the platform and other users. They had fears that a public association with dementia may make one a target for online scams or identity theft. Others explained how people from different generations or cultural backgrounds may be more averse to sharing dementia research content.

Professional experts shared consonant concerns about stigma related to the word "dementia," the negative emotions it may elicit (e.g., bad memories, fear), and how this reduces engagement with prevention research. Growing up in a predominantly Cambodian community, one participant described how social meanings of stigma are co-created:

"[...] there are times where I would hesitate to post [dementia research] because maybe I feel judged by my friends, or telling them I had a secret about me, like I might have it, or it runs in my family. You know how families are, they are like, 'oh no, we keep it quiet [...]" (LE008, experience).

Conversely, participants discussed how social media affords a particular anonymity that may pose methodological issues for dementia research. The ability to obscure one's identity risks false or deceptive responses and lacks a denominator to better understand the study population.

For many participants, rampant social media misinformation makes it difficult to discriminate legitimate dementia research content. To gauge trust, many experts by experience relied on the reputation of the organization sharing the information (e.g., university, community group). However, these experts were strongly averse to for-profit interests or what they regarded as being used as a means to an end, particularly in response to one of the recruitment vignettes. A participant explained how competing content alters perceptions of dementia research on social media and requires extra effort to validate: "There is a lot of spam and fake news [...] Do I have time to fact check this information and how much do I trust it?" (LE005, experience).

Some professional experts reported concerns about communicating complex research concepts into the rapid, short-form consumption norms of social media. One dementia researcher wrestled with the challenge of presenting new evidence to the public and reconciling it with different or contradictory evidence in older posts.

#### *Theme 4: Theoretical reach vs. actual access*

This theme highlights the justice-related concerns of participants and the conflicting aspects of social media's unclear reach.

Most participants identified greater reach when using social media. In their responses, social media removes the ivory tower phenomenon by going beyond traditional academic, or clinical spaces, and diversifying prospective participants through connected networks. Participants reported that younger, healthy age groups are more likely to use and benefit from social media. One research coordinator stated: "Social media could actually make them think, 'oh, maybe I could get involved in this,' particularly when we are looking for healthy people." (005, professional).

However, most professional experts reported limited success improving sociodemographic diversity with social media, mainly for recruitment. Disparities in digital literacy or internet access contribute to age-related, health-related (i.e., onset of dementia symptoms), or socioeconomic barriers. On geographic inequity, UK researchers worried about disappointing individuals in rural and remote areas who view research opportunities on social media but live too far to participate.

Participants reported the critical role of messaging when communicating the relevance of prevention content. Language identified as alienating certain communities included: posting only in English, using acronyms or jargon, using primarily Western understandings of dementia, and posting language at a high literacy level. One dementia researcher discussed the constraints of prescribed language in prevention trials:

"[...] they [study sponsor] have already given you a set of words that you can and cannot use. It is called approved language [...] The hard part is making sure nobody misunderstands because they are written from an academic point of view [...] [A prospective participant] may say, all right, if I am asymptomatic, or I do not have any issues [...] why do I need to be in the study then?" (010, professional).

#### *Theme 5: Antecedent influences on engagement*

Individual level factors may influence how risk and benefit are weighed on social media, affecting subsequent engagement.

Almost all the experts by experience reported a personal connection to dementia that motivated their interest in prevention research and health-oriented action. Those who reported a family history often made references or judgements of their own subjective risk. One researcher contemplated the impact of social media on individuals with existing brain health worries: "It [social media] could be potentially harmful, and we need to understand whether we are creating health anxiety in individuals who are constantly worried about what

might happen to them in 20- or 30-years' time [...]" (009, professional).

Some experts by experience reported that feeling hopeful was a motivating factor for engaging on social media. One participant described hope as both an outcome and a means of motivation for using social media: "There is more hope now in using social media to help advocate dementia and hoping that with the rise of technology we can help prevent it more than treating it." (LE008, experience).

Understanding that people may seek hope on social media, professional experts wanted to avoid over-promising or eliciting false hope. A dementia researcher highlighted the importance of broader engagement as education prior to a study: "one big problem with social media is that, especially with underrepresented populations, that you need a lot of awareness and education [beforehand] because you can create a lot of expectations, especially with clinical trials." (013, professional).

#### *Technical elements*

Participants reported some practical approaches and considerations to social media post construction for dementia prevention (see Table 2 for a summary).

While many suggestions in Table 2 are broadly applicable (e.g., study details, cite sources), there were some dementia-specific considerations. Participants reported a preference for positive messaging that departs from negative or stigmatizing representations of dementia. One professional expert explained that the social media audience includes people living with dementia, and that any content shared ought to be considerate of the needs of the dementia community. One person living with dementia stated that lifestyle factors typically associated with early prevention are also relevant to living well with a diagnosis of dementia, and that this overlap is insufficiently acknowledged. This participant also emphasized communication needs for social media "[...] no acronyms, none, zero. Many people with dementia cannot do acronyms." (LE010, experience).

Participants from both expert groups reported platform-specific norms and affordances that influence the effective sharing of content. Some examples included using hashtags, image-based posts, and short format text. Although many professional experts discussed engagement through the use case of recruitment, both expert groups introduced topics related to education, awareness, and advocacy on social media.

Despite both vignettes being about recruitment, many experts by experience expressed a high interest in the dementia-related facts and figures in the posts. These details noticeably captured their attention and were often brought up for comment. One expert by experience explained that including study incentives demonstrates a reciprocity and respect for their efforts which is valued

**Table 2.** Technical elements of social media engagement for dementia prevention research

Technical element	Action or consideration
Platform Affordances	
	Make use of platform features; employ social media norms.
Presentation	
	Personalize the post (approachable vs. clinical).
	Use less text, more use of other senses (graphics, videos).
	Aim for positive messaging.
	Remove assumptions about what users actually know.
Content	
Information	Provide dementia facts and research updates.
	Cite any facts with reputable sources.
	Avoid jargon or acronyms.
	Include critical features of the study (location, eligibility, impact, expiry date of opportunity, precise ask).
	Include assurances of ethics review and approval.
	Contextualize the disease.
Effort or Commitment	Remain attentive to participant aversion to drugs or being a «guinea pig.»
	Specify commitment in post.
Incentive	Provide an incentive.
	Consider cultural or individual differences in motivation.
	Be aware of potential to compromise authenticity of research participation.
Patient-centered	
	Co-design and put the participant at the center of the research.
	Tailor the approach to different communities with the community.
	Partner with individuals from community.

by members of different cultural or socioeconomic backgrounds.

Professional experts acknowledged that needs and values will change across patient groups, communities, cultures, geographical regions etc. Due to this reason, some reported that co-designing or a patient-centered approach could facilitate appropriate social media communication.

## Discussion

The study aim was to elucidate the risks, benefits, and values of parties for whom dementia prevention research is relevant and the ways social media engagement is enacted, modified, and constructed. Through interviews with professional and community experts, here we report ethical and contextual factors of social media engagement in dementia prevention research.

On the ethical factors influencing engagement (RQ1), the findings suggest that there is a crucial need for practical guidelines when using social media for dementia prevention research. Our results demonstrate that there is little to no uptake of existing social media frameworks in dementia prevention research. Experts

rely on formal and informal ethical input, as research ethics boards do not address the full range of social media engagement. These data support previous social media reports in health research (30). Professionals sought methods of strategic communication on social media, such as responding to misinformation and online criticism. Being ill-equipped to handle online dialogue may contribute to sub-optimal engagement of important dementia prevention research. From an organizational policy domain, dementia professionals could benefit from contextual guidance to interpret and construct ethical social media practices attending to the needs of their patient population and the norms of their field.

Our findings outlined several risks impacting how individuals engage with dementia prevention research on social media. Professional experts would typically, but not exclusively, take a principled “do no harm” approach to ethical social media use. This was evident in their repeated utterances to, for example, avoid eliciting false hope, health anxiety and other negative emotions, dispelling misinformation, and handling online criticism. Experts by experience highly valued learning about prevention research, believing that social media resources contribute to altruistic conceptions of the



common good. However, many hesitated to leave public traces of engagement on dementia content, due to risks of predatory practices or stigma-related judgments about one's personal health or family history. In a recent scoping review of dementia education and training for the public, there was no discussion of stigma reduction in the prevention studies (31). In light of this, our data suggests that discussions of dementia prevention research on social media ought to include stigma-reducing measures when sharing research findings, qualifying future risk, and addressing online dialogue in social media comments. Social media guidelines also ought to include methods for mitigating harm related to misinformation. In our study, participants weighed varying degrees of truth ranging from misunderstandings of complex scientific information, content with an ulterior purpose (i.e., spam), to false information. Organizational reputation aided the vetting process. This is evidenced by participants' aversion to commercial studies and preference for trusted organizations and institutions. However, reputation alone does not facilitate public education of the features of misleading or false online research narratives (32). Altogether, these data support existing knowledge (11, 33) that factors outside access influence engagement with dementia prevention research. Using social media to overcome prevention recruitment disparities calls for approaches that address ethical risks specific to the sociotechnical context.

Access is extended in many ways on social media, and it is limited in other ways. Most participants believed that younger aging populations—who are unlikely to be found in clinics—could benefit from exposure to prevention research content on social media. However, professional experts reported justice-related concerns that social media did not improve sociodemographic diversity for recruitment; this finding is consistent with diverse minority recruitment patterns in Alzheimer's disease trials (11, 34). Participants described social media use as an indicator of health, age, urban/rural dwelling, ethnoracial or cultural identity, or socioeconomic status. Language and literacy-related barriers contributed to access disparities and difficulties communicating the relevance of prevention trials to broad populations. Research guidelines on social media post construction could address messaging and language contributing to social exclusion, whereas it is less clear how guidance could apply to other access disparities, such as internet connectivity (i.e., socioeconomic status).

Our findings include a number of technical suggestions to guide the process of social media outreach. Many suggestions align with previous literature of science communication (35) or dementia research recruitment (33, 36), including, attention to post length, avoiding jargon, clarifying assumptions, appropriate compensation, providing relevant facts, amongst others. An important dementia-specific consideration was that prevention research content on social media can be relevant to and

viewed by people living with dementia. As such, the post creation process should incorporate the needs of the broader dementia community.

The results support a conceptualization of social media engagement for prevention research (RQ2) as a dialogic continuum that is irreducible to perceptible online interactions. First, it is a process of communication that involves sustained education, awareness, and relationship-building. This aligns with justice-informed approaches to aging research engagement, where pre-participatory states are outcomes in and of themselves (17). Second, users exhibited a spectrum of social media activity, including abstaining from visible interactions to avoid negative experiences. Other users described acts of care for interpersonal relationships by sharing prevention research to intentionally discreet audiences. Our investigation includes contextual factors that reveal specific motivations or challenges, such as subjective risk of dementia in healthy individuals (12). The findings represent a broader understanding of social media research engagement for prevention across affective, cognitive, and behavioral phenomena.

Our study is the first of its kind to include diverse expert views on the ethics of social media engagement in dementia prevention research. Previous social media studies explored challenges and ethical use in other areas of health research (e.g., diabetes, smoking cessation, cancer, HIV) (37–40) or presented ethical considerations for the purposes of recruitment, tracking, tracing (20, 30), or accessing public data (41, 42). Few studies explore the ethical aspects of social media engagement outside study involvement (43). Uptake of existing social media frameworks may be higher in social media-specific research fields (42). Our paper contributes diverse expert views of the social dependencies between dementia prevention research and social media use.

### *Limitations*

There are some limitations to our study. We did not distinguish between primary and secondary dementia prevention in the interviews, which are stages of health carrying important ethical and epistemic differences (9). Due to time restraints, vignettes consisted of only two study recruitment posts rather than diverse examples of dementia prevention content. Hypothetical scenarios may not capture real world engagement with dementia prevention research on social media, such as the directionality of engagement and behavioral outcomes. There are ethical factors (e.g., autonomy) that social media guidance may not address directly. Future research could investigate the relationship between exposure to dementia prevention research on social media and subsequent health-seeking behaviour. The interviews were in English and with participants mainly from Western countries.

Another limitation of our study is that some ethical

issues may be mostly relevant to a type of post, e.g., recruitment, or public health education. An engagement perspective allows us to analyze the spectrum of overlap between recruitment, public health, and other research activity situated within a specific health research and technological context. The approach, like other approaches, will be limited in some respects and more insightful in other aspects of analysis. This does not preclude separate analysis of more specific ethical perspectives. Engagement is a lens to understand social media as disparate, dynamic media forms that facilitate social and relational exchanges between researchers and affected communities. Thus, our analysis contributes to evolving theory surrounding the ethics of engagement in research.

## Conclusion

Within the dementia prevention research context, understanding the views of the people affected by social media use can help guide ethical practice. Our qualitative interview findings indicate that dementia prevention research could benefit from social media guidelines reflecting the values and needs of the dementia research and broader community. These will inform the next project phase focused on the creation of guidelines to minimize risk, maximize benefit, and strive towards digital equity.

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