

# Ethical factors influence how people engage with dementia prevention research on social media.

“ a lot of people probably will not want to be associated with the word ‘dementia’  
- CM011

“ it took me a long time to understand Twitter  
- CM007

“ I honestly have never seen a social media guideline for researchers ever  
- R002

“ I think you are empowering people who read those tweets  
- R001

CM = Community Member; R = Researcher

## Towards ethical social media use in dementia prevention research

Viorica Hrinco<sup>1</sup>, Grayden Zaleski<sup>1</sup>, Julie M. Robillard<sup>1,2</sup>

<sup>1</sup>Division of Neurology, Department of Medicine, University of British Columbia <sup>2</sup>BC Children's and Women's Hospitals

### Objective

**IDENTIFY ETHICAL CONSIDERATIONS, MOTIVATORS, AND BARRIERS THAT INFLUENCE ENGAGEMENT WITH DEMENTIA PREVENTION RESEARCH ON SOCIAL MEDIA.**

### Introduction

Asymptomatic individuals may not be aware that dementia prevention research is relevant to them [1].

Researchers can use social media to share dementia prevention research outside clinical settings to the broader public [2].

#### ETHICS OF SOCIAL MEDIA

Ethical considerations arise on social media, e.g., privacy, capacity, access, misinformation.

Current social media guidelines for research:

- Are broad.
- Are not tailored to dementia prevention.
- Were not created with input from the dementia community.

### Methods

#### Semi-structured interviews

- n= 14 experts by experience
- n= 15 professional experts

**Qualitative thematic analysis** of interview transcripts organized into major themes guided by a sociotechnical ethics framework.

### Future work

We used this data to co-create new social media recommendations which are subject to evaluation and dissemination.

### Results

Five major themes are ethical elements identified as influencing engagement with dementia prevention research on social media [3].



#### lack of ethical guidance

No uptake of existing social media guidelines by dementia research professionals.

Unclear how to respond to misinformation or public dialogue on social media.



#### mutually beneficial goals

Social media provides communication pathways supporting various degrees of engagement.

Empower autonomy and agency for seeking information.

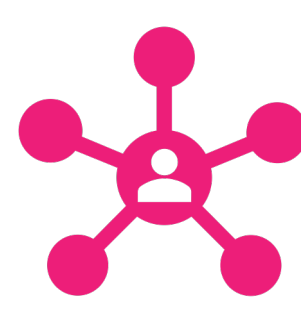


#### risk factors limiting engagement

Stigma and negative emotions surround the word 'dementia.'

Unclear who to trust and how to tell truth from misinformation.

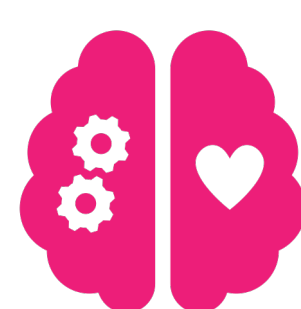
Worries about predatory practices on public platforms.



#### theoretical reach vs. actual accessibility

Language must be easy-to-understand to avoid alienating people.

Disparities across language, health, age, socioeconomic, and geographic variables.



#### antecedent influences on engagement

Family history and interest in research motivate social media use.

Maintaining a healthy level of hope; managing expectations about the possibilities of research on social media.

### Discussion

To support reliable ethical decisions, research professionals could benefit from social media guidance specific to dementia prevention.

Future recommendations should address ethical factors, expectations of engagement, and the needs of the broader dementia community to limit social exclusion.



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[1] Fargo et al. The crisis in recruitment for clinical trials in Alzheimer's and dementia: An action plan for solutions. *Alzheimer's Dement.* 2016. [2] Hrinco V, An Z, Joseph K, Jiang YF, Robillard JM. Dementia Research on Facebook and Twitter: Current Practice and Challenges. *J Alzheimer's Dis.* 2022. [3] Hrinco V, Zaleski G, Robillard JM. Ethical Considerations at the Intersection of Social Media and Dementia Prevention Research. *JPAD.* 2024