Towards ethical social media use in dementia prevention research

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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
- mutually beneficial goals
- risk factors limiting engagement
- theoretical reach vs. actual accessibility
- antecedent influences on engagement

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.

References
[3] Hrincu V, Zaleski G, Robillard JM. Ethical Considerations at the Intersection of Social Media and Dementia Prevention Research. JPAD. 2024