

Patient Engagement in Research on Dementia:

Perceptions from Researchers in a Multidisciplinary Research Consortium

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Background

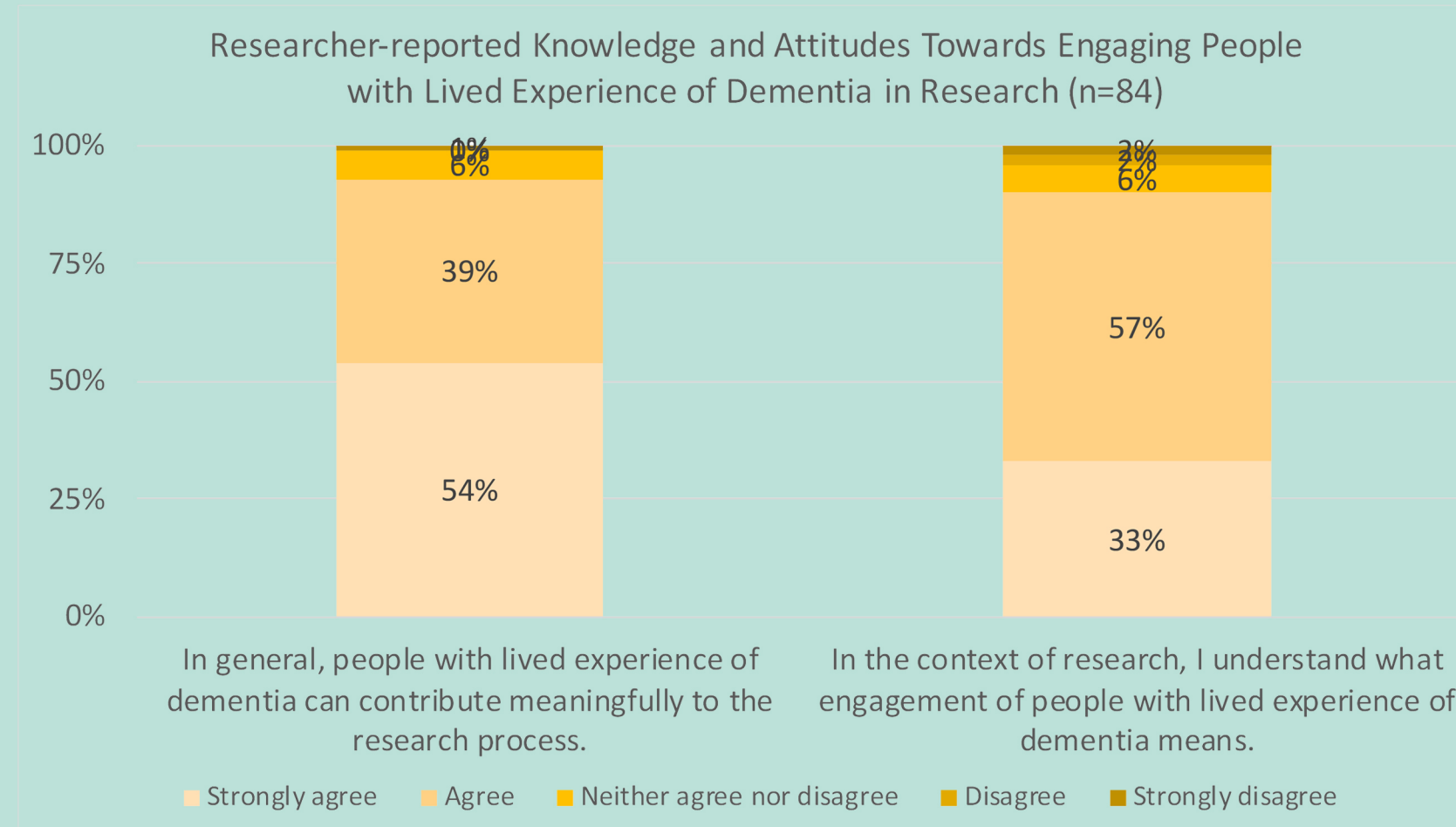
Patient ‘engagement’ or ‘involvement’ in research on dementia refers to including people with dementia and their friends, family and caregivers in the research process – not as study subjects, but as collaborators in planning, conducting and communicating research. It is not new, but it is becoming much more common.¹ Researchers are being encouraged to consider approaches to patient engagement in research on dementia,² but methods for incorporating, evaluating and adapting engagement activities in different types of research are not well-defined.

OBJECTIVE: describe knowledge, attitudes, and activities related to patient engagement in a multidisciplinary network of dementia researchers.

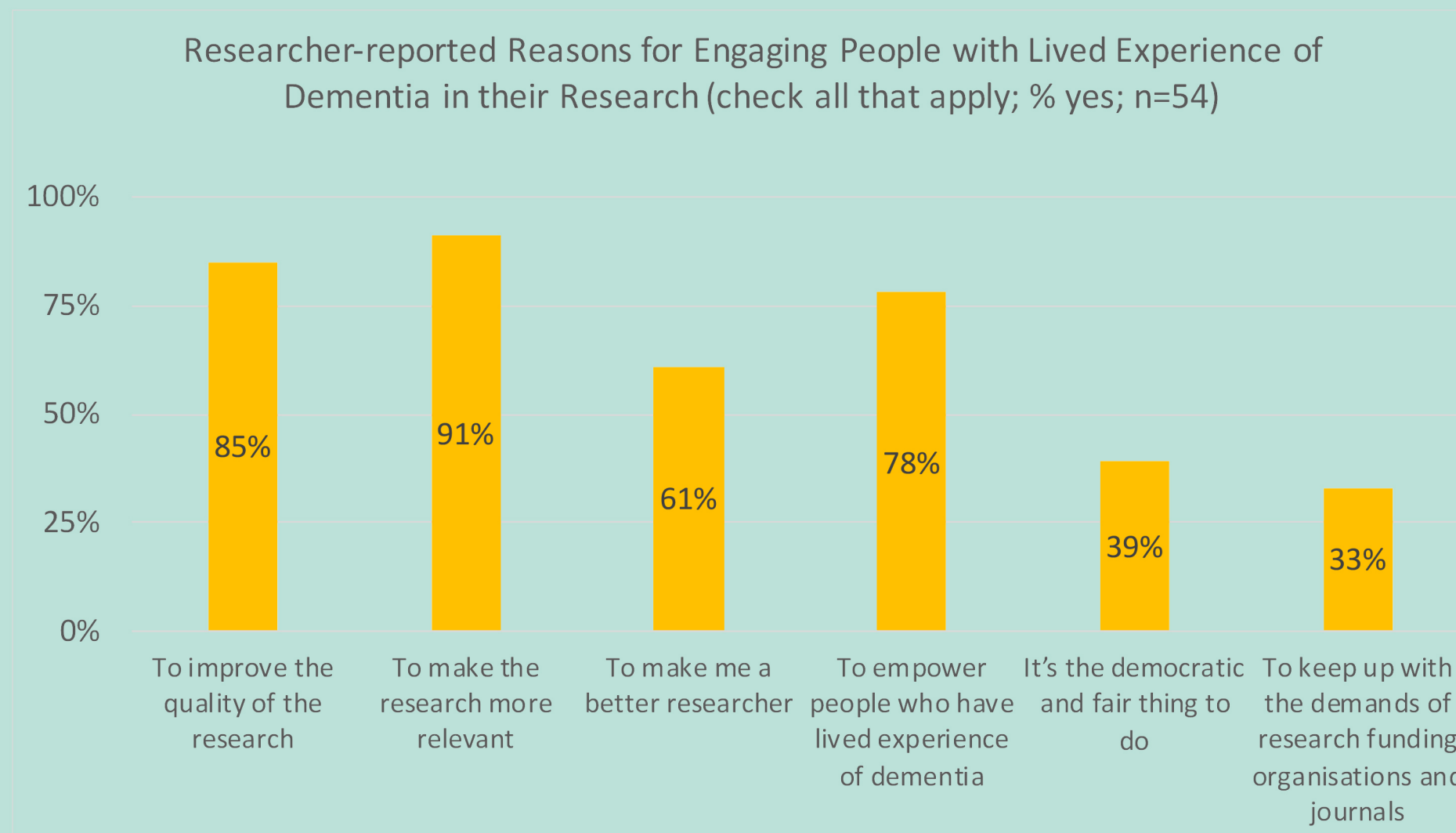
Methods

Secondary analysis of an online, anonymous, cross-sectional survey conducted by the Canadian Consortium on Neurodegeneration in Aging (CCNA) Engagement of People with Lived Experience program to assess CCNA researchers’ knowledge, attitudes, and activities related to patient engagement in dementia research. The questionnaire was developed in English then translated into French. Data were collected continuously between September and December 2019. The study was approved by the University Health Network (UHN) Research Ethics Board (20-5459).

Nearly all (93%) researchers who responded to the survey agreed or strongly agreed that people with lived experience of dementia can contribute meaningfully to the research process.



For researchers already engaging people with lived experience of dementia in their research, the most common motivations were improving the quality of the research (85%) and making it more relevant (91%) as well as empowering people with lived experience of dementia (78%).



Results

Respondent Characteristics: Common Alzheimer’s and Related Dementias Research Ontology category³ (n=84)

	n	%
Dementia care & impact of disease	36	43%
Translational research & clinical interventions	14	17%
Diagnosis, assessment & disease monitoring	13	15%
Brain aging & common mechanisms related to dementias	9	11%
Population studies	7	8%
Other or not stated	5	6%

Conclusion

Most CCNA researchers are enthusiastic about opportunities to engage people with lived experience in their research and many have experience doing so. These data will be used to describe how researcher knowledge, attitudes and activities differ according to type of research they conduct.

References

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