

Promising Practices for Engaging People with Lived Experience of Dementia in Advocacy and Research

Findings from a modified Delphi study

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BACKGROUND

Meaningful engagement of individuals with lived experience of dementia is increasingly prioritized in advocacy and research, yet practical implementation guidance is absent.

We conducted a global modified Delphi study to identify a consensus-based, international framework of promising practices to guide such efforts.

METHODS

- Initial practices were derived from structured sessions at AAIC 2025, Walking the Talk for Dementia 2025, and with Atlantic Fellows for Equity in Brain Health at Trinity College Dublin.
- A bilingual, three-round modified Delphi study was conducted. All responses were anonymous.

Survey 1

- Invited participants to generate new ideas of "Promising Practices", nearly 500 ideas generated.
- Qualitative synthesis of these suggestions with previously identified ideas, with thematic categorization.
- Advisory group of people with lived experience and partner organization representatives reviewed and refined items for the next survey.

Survey 2

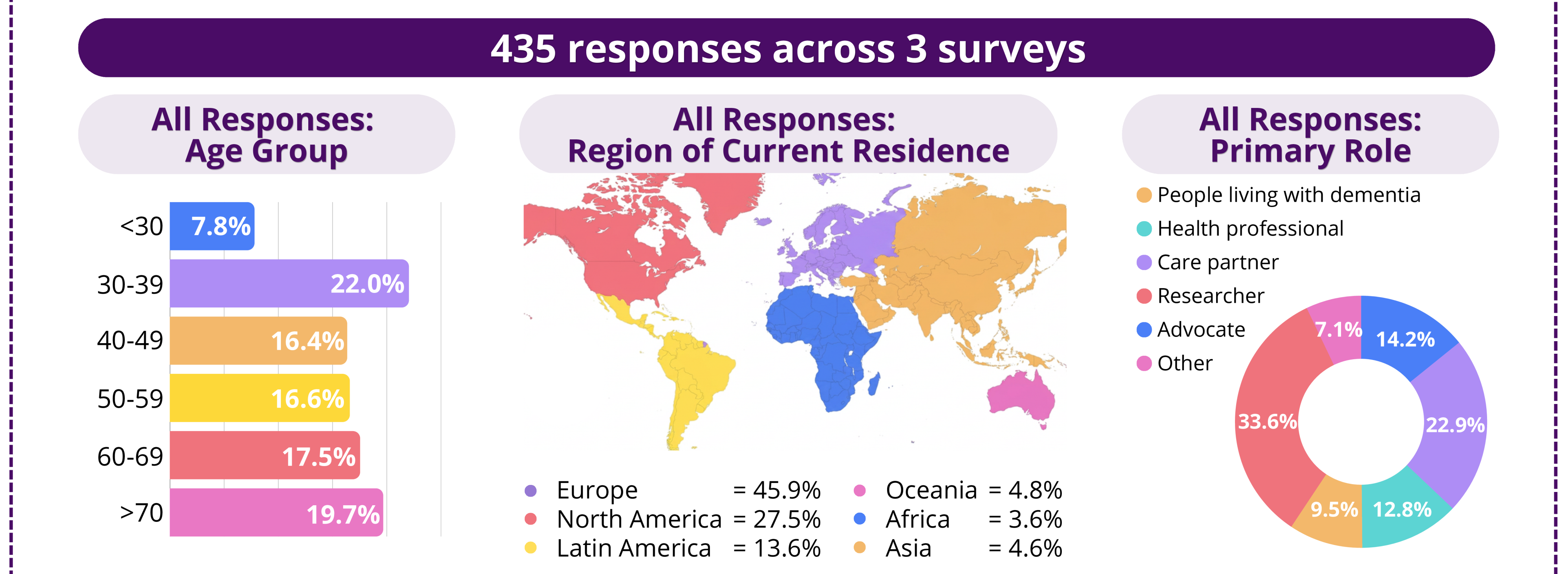
- Participants rated importance of 6 practices in each of 8 themes on five point scale.

Survey 3

- Participants ranked 6 practices in priority order within each of the 8 themes.

RESULTS

- A total of 377 participants registered** and were invited to each survey regardless of prior response.



- Eight themes were identified:**
 - Trust and relationships
 - Dignity and autonomy
 - Meaningful participation
 - Clear communication
 - Collaboration
 - Cultural responsiveness
 - Recognition of contributions
 - Barriers to participation
- Final outputs comprised prioritized practices within each theme and an overall ranked list of top practices. Six practices were synthesized for each theme, and subsequently ranked.

CONCLUSIONS

- Findings demonstrate feasibility of creating an international, multi-stakeholder framework of promising engagement practices.
- Practices provide actionable guidance to organizations and individuals to more effectively and equitably engage people with lived experience of dementia in research and advocacy.
- Partner organizations, with both national and global reach, will share this guidance to support more meaningful, inclusive, and equitable collaboration across dementia research and advocacy.

ADDITIONAL MATERIAL

A Guidance Document for using the Promising Practices in different contexts will be available in September.

Please scan the QR if you'd like to receive it

