

**Engaging Persons Living with Dementia in the Research Process: Best Practice Considerations
from a National Dementia Meeting**

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Today more than 35 million people and families worldwide live with dementia.¹ Although there is no cure for dementia, years of investment have yielded many behavioral and other nonpharmacologic programs and interventions aimed at helping people live better with dementia² and to support dementia caregivers.³ Despite promising evidence about these interventions' statistical and clinical significance, there is a lack of impact from this evidence.⁴ It is not clear whether this reflects genuine ineffectiveness in “the real word” or a failure in implementing this evidence.

One approach to reduce the translational gap of dementia interventions has been to increase the involvement of stakeholders in dementia in research. Engaging patients and communities in the research process is an increasingly common approach that can improve the value and relevance of research outcomes.⁵ However, challenges and barriers often exist for effectively including people living with dementia and their caregivers in research activities.⁶ In this issue, Frank et al.⁷ share best practices for

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engaging persons living with dementia (PLWD) in the planning and execution of a national dementia research meeting. For the *2017 National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers*, Summit leaders convened a Stakeholder Group comprised of PLWD to provide their perspectives on Summit agenda content, selection of Summit speakers, and Summit research recommendations. Members of this PLWD Stakeholder Group were identified by nomination, and all experienced mild or moderate symptoms of a cognitive disorder. Nearly half of the 58 research recommendations that were included in the final Summit report expressed ideas that were contributed by the PLWD Stakeholder Group, indicating that they made a significant impact on the outcomes of the meeting.

At the conclusion of the Summit, the PLWD Stakeholder Group identified several best practices for forming and facilitating stakeholder groups comprised of persons living with dementia, including strategies for recruiting members, addressing accommodations, and establishing group processes. These best practice recommendations and Frank et al.'s discussion are important, as they attempt to address some of the unique barriers and challenges that have been identified in engaging individuals with dementia in research activities.

One challenge the authors cite is addressing members' capacity for participation and adapting responsibilities as needed with potential disease progression. Frank et al. recommends offering multiple levels of participation within the Stakeholder group to address members' varying strengths and needs. However, it is important for researchers to avoid making assumptions about a member's capacity, as it can fuel stigma around dementia and potentially create further barriers to research engagement.⁶ Rather, Frank et al. suggests using group-initiated strategies for supporting and assisting fellow members who are experiencing disease progression.

It is also important to remember that individuals living with dementia, are not a homogenous population, but rather a diverse group of people with a wide array of perspectives, interests, skills, and abilities. The

PLWD Summit Group represented a variety of dementia diagnoses, however, Frank et al. noted that Group members tended to be high-functioning, hold advanced degrees, and be familiar with the research process. Older adult and PLWD Stakeholder groups to date have been recruited via convenience sampling due to challenges with random sampling, however this may result in underrepresentation of individuals with advanced stages of disease, less education, or who are racial or ethnic minorities.⁸ Additionally, researchers who engage PLWD Stakeholders should carefully consider the role of caregivers in supporting their loved ones' participation. While caregivers can support PLWD to more effectively contribute to stakeholder groups, it is important to ensure that the perspectives of PLWD are still being heard. Including caregivers can also introduce new interpersonal dynamics that may interfere with PLWD providing open feedback.⁹ Researchers should offer choices to PLWD on whether and how their caregivers should assist,⁶ and provide guidelines to these caregivers on their level of involvement.⁹

Frank et al. also identified key strategies and processes to ensure quality participation and feedback of its members. The PLWD Stakeholder Group established clear expectations for members on the monthly time commitment and expected duration of involvement. Additionally, they designated two non-PLWD individuals to be group facilitators to manage schedules, group assignments, and aid participants with videoconferencing technology.⁷ An additional strategy that can be considered to facilitate high-quality participation during the stakeholder process is to compensate people for their time and any associated travel or accommodation costs.

Frank et al.'s approach provides a useful framework for how other researchers can incorporate PLWD's perspectives into dementia research development, execution, and implementation. Additionally, learning from the challenges presented by Frank et al. and others invites new and innovative ways for engaging PLWD and caregivers in the research process.

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References

1 M Prince, R Bryce, E Albanese, *et al.* The global prevalence of dementia: a systematic review and meta-analysis. *Alzheimers Dement*, 9 (2013), pp. 63-75.

2 VA Moyer, on behalf of the U.S. Preventive Services Task Force. Screening for cognitive impairment in older adults: U.S. preventive services task force recommendation statement. *Ann Intern Med*, 160 (2014), pp. 791-797.

3 LN Gitlin, K Marx, IH Stanley, *et al.* Translating evidence-based dementia caregiving interventions into practice: state-of-the-science and next steps. *Gerontologist*, 55 (2) (2015 Apr), pp. 210-226.

4 M Vernooij-Dassen, E Moniz-Cook. Raising the standard of applied dementia care research: addressing the implementation error. *Aging Ment Health*, 18 (2014), pp. 809-814, 10.1080/13607863.2014.899977

5 LP Forsythe, KL Carman, V Szydowski, *et al.* Patient engagement in research: early findings from the patient-centered outcomes research institute. *Health Affairs*, 38 (2019), pp. 359-367.

6 J Bethell, E Comisso, HM Rostad, *et al.* Patient engagement in research related to dementia: a scoping review. *Dementia*, 17 (2018), pp. 944-975.

7 L Frank, E Shubeck, M Schicker, *et al.* Contributions of persons living with dementia to scientific research meetings: best practices from the national research summit on care, services and supports for persons with dementia and their caregivers. *Am J Geriatr Psychiatry*, 28 (2020), pp. 421-430.

8 I Schilling, A Gerhardus. Methods for involving older people in health research: a review of the literature. *Int J Environ Res Public Health*, 14 (2017).

9 D Gove, A Diaz-Ponce, J Georges, *et al.* Alzheimer Europe's position on involving people with dementia in research through PPI (patient and public involvement). *Aging Ment Health.*, 22 (2018), pp. 723-729.