

Lived Experience Panel Frequently-Asked Questions (FAQ)

1. What is the National Institute on Aging IMPACT Collaboratory?

IMPACT is The National Institute on Aging IMbedded Pragmatic Alzheimer's disease (AD) and AD Related Dementias (AD/ADRD) Clinical Trials (IMPACT) Collaboratory. The IMPACT Collaboratory conducts research on Alzheimer's disease and related dementias, specifically, embedded pragmatic clinical trials (ePCTs).

2. What is an embedded pragmatic clinical trial?

An embedded pragmatic clinical trial (ePCT) is a trial based on implementing an intervention that can be "embedded" within routine care provided within a healthcare system, agency or organization, or other non-healthcare based organizations. The intervention is implemented in a "real-world" environment by practicing clinicians or non-clinical staff, not interventionists. A core component is that the intervention can be maintained for real-world use and sustained beyond the scope of a trial. Most ePCTs utilize data available from electronic health records, administrative data, or claims data to assess effectiveness outcomes.

The NIH Health Care Systems Research Collaboratory [Living Textbook of Pragmatic Trials](#) is a helpful resource to learn more about ePCTs.

3. What is the role of the Lived Experience Panel?

The role of the Lived Experience Panel is to provide ongoing feedback including:

- What are important topics for research?
- How can studies be designed so that participation is easier for people living with dementia and their family members and care partners?
- How can people with lived experience of dementia be involved in design of research and implementation of research studies?

Panel member's feedback will inform the activities of the IMPACT Collaboratory.

4. Why is the IMPACT Collaboratory seeking individuals living with dementia and care partners to participate in the Lived Experience Panel?

It is critical to include the perspective of people living with dementia as well as care partners in the discussion of necessary care, services, and supports for those affected by dementia. Including the personal experiences of those living with dementia and care partners can provide vivid examples that help researchers, professionals, and other stakeholders better understand and prioritize the most urgent needs.

5. What are the criteria for nominees?

Nominees for the Lived Experience Panel should fit one of the following categories:

- Individuals with a documented diagnosis of early stage Alzheimer's, Mild Cognitive Impairment (MCI) or other early stage dementia.
- Care partners representing his or her own experience caring for an individual living with dementia.
- Care partners/family members who can represent the perspective of one or more individuals living in the middle or late stage.

Additionally, nominees should have the ability to participate independently in conference/video calls and use email. Some guidance will be provided during the orientation.

6. When will the meetings occur and what is the term for members?

The meetings will occur for 90 minutes every 3 months over video and/or conference calls. The term on the panel will be a minimum of (1) year, with potential for some members to serve longer terms.

7. How many individuals will be invited to participate in the Lived Experience Panel?

The Panel will be composed of 12 individuals.

8. What does the nomination process consist of?

New members will be selected annually. Individuals interested in participating can complete the [Lived Experience Panel Interest Form](#) and a project leader will follow-up via email with a link to the online nomination form when it opens in October 2020. Project leaders will schedule telephone interviews with some candidates in order to learn more about their experience living with dementia or as a care partner. Because nominations for the Lived Experience Panel are collected year-round, if the maximum number of nominations are received for the next term, we will notify you via email to discuss other options.

9. What types of questions will be asked during the phone interview?

The phone interview is intended to be a casual conversation that provides the project leaders the opportunity to learn more about the nominees' experiences. Nominees may be asked to provide a description of the warning signs, process toward receiving a diagnosis, impact of diagnosis on the individual, support services and gaps in care. Nominees will also be asked to describe their interest in participating in the Lived Experience Panel and his/her thoughts on the value of including the voices of people living with dementia and care partners in dementia research.

10. What type of support is provided to panel members?

Panel Members should be able to participate in conference calls, use email and articulate their thoughts on the topics being discussed. The project leads will manage all meeting logistics so panel members can focus on the work at hand.

11. Who should candidates contact if they have any questions?

[Kerry Lanigan](#), Associate Director of Care and Support with the Alzheimer's Association.
