

About Public Involvement

- To ensure that **research accurately reflects the preferences, needs and priorities of members of the public**, their perspectives - including experiences and concerns - need to be included in different aspects of research processes and outputs/results.
- Public Involvement (PI) has been shown to improve the **quality of research** by enabling researchers to **benefit from the lived experience** of people with dementia. Also, it helps ensure that research is **ethical, transparent** and **gives people with dementia a voice**, reflecting the principle of “nothing about us without us”.

As dementia-related research is now **increasingly focusing on people who do not yet have dementia but are at higher risk** (e.g. diagnosed with Mild Cognitive Impairment or Subjective Cognitive Decline), people from these groups should also have the opportunity to voice their opinions.

Alzheimer Europe would like to invite individuals who are affected by or interested in dementia and brain health to join this European PI pool.

→ This platform allows members of the public (excluding health and social care professionals, service providers and students) **to share their views on various research-related topics and projects.**

→ You will be invited to participate in **online or in-person consultations, focus groups, written discussions** and **brief surveys.**

In particular, members of the PI Pool will have the opportunity to provide input on different aspects of **ongoing European research initiatives** (e.g. on new technologies and artificial intelligence-based approaches to dementia prevention or management, palliative care, dementia risk prediction etc.).

We particularly welcome:

- People with dementia
- People at higher risk of dementia or with memory or other cognitive problems
- Carers, supporters or family members of people with dementia
- Additionally, we are very keen to include the perspectives of members of minority and marginalised groups and cultures (such as people from minority ethnic groups, from the LGBTQ+ community or living in rural areas or residential care settings).

Please note it is not intended that this platform should involve members of the public in research as **research participants**: PI is about members of the public, including those with cognitive impairment or dementia providing input on the research process within specific European dementia research projects (e.g. related to the design and conduct of research, the ethical implications of a research project etc.).

WHAT CAN YOU EXPECT FROM PARTICIPATING?

By registering for the Alzheimer Europe PI Pool, you will be invited to:

- Provide your views on **topics that are of interest to you** (examples of topics include: the use of artificial intelligence in dementia research, dementia-risk disclosure, societal needs of people with dementia, discrimination, stigma, palliative care etc.).
- **Indicate** which activities and topics are of interest to you.
- Get **updates** on how your feedback/input has helped inform projects and advance research for people with dementia.
- Join a growing **community of people from different European countries** interested in sharing their views on dementia-related topics.
- Receive **regular information and updates** about ongoing European **research** developments in the field of dementia.

- Get **information about interesting events** (e.g. webinars hosted by experts on dementia and brain health).
- Provide written feedback, if you prefer, in **other European languages** (covered by AE staff) such as Spanish, Italian, French and German.
- You will be able to unsubscribe from the pool at any time. More information about our privacy policy can be found here: [AE General Privacy Policy](#).

WHAT DO WE NEED FROM YOU?

In order to join the PI Pool, we need you to:

→ Fill in the registration form and provide a little bit of information about yourself

→ Be willing to commit to joining at least one PI activity a year in which you share your views either in writing or in a discussion (in English), with the possibility to unsubscribe to the pool at any time.