

# *Policy for involvement in EU projects*



## Background information

Alzheimer Europe is the umbrella organisation of 41 national Alzheimer's associations from 36 European countries. The organisation is an accredited patient organisation at the European Medicines Agency, with participatory status at the Council of Europe. Alzheimer Europe partners with **various EU projects**, funded through programmes such as Horizon Europe and the Innovative Health Initiative. The organisation is also accredited with the Luxembourg Ministry for Research and is entitled to receive funding from the Luxembourg "Fonds National pour la Recherche" for its involvement in projects funded through the JPND, ERA-NET and other joint funding schemes.

In these projects, Alzheimer Europe:

- leads **public involvement activities**, providing the views of people with or at risk of dementia, their caregivers and supporters,
- contributes to the identification, analysis and discussion of **ethical and societal issues** raised by the research,
- analyses the **national and European policy contexts** for research, supporting implementation, impact and sustainability,
- convenes meetings to **engage and involve key stakeholders** including national Alzheimer's associations, clinicians, regulators, industry representatives and policymakers, and
- supports or leads the **dissemination and communication** of the project to the wider dementia community and the general public.

## Contributions to research projects

Alzheimer Europe welcomes the opportunity to contribute to European research projects on dementia, brain health, and related areas. Alzheimer Europe has developed the following valuable resources which can support research activities:

- the European Working Group of People with Dementia, composed of 13 people with dementia who have been nominated by their national associations, can provide input on how research is designed, conducted and disseminated,
- the European Dementia Carers Working Group, composed of 15 carers, relatives and supporters of people with dementia who have been nominated by their national associations, can provide input on how research is designed, conducted and disseminated,
- The European Public Involvement Pool, which comprises people who are affected by, or interested in dementia and brain health, can provide input on how research is designed, conducted and disseminated,

- its established network of European and national policy makers, including its European Alzheimer's Alliance (with more than 75 Members of the European Parliament who have an interest in dementia) and the European Group of Governmental Experts on Dementia (with representatives from national health ministries and government agencies).
- its established network of research and health stakeholders, including the European Medicines Agency and World Health Organisation-Europe, together with clinical, research and civil society organisations such as the European Academy of Neurology, European Patients' Forum, INTERDEM and the European Alzheimer's Disease Consortium,
- its well-developed communication tools such as its [website](#), its "Dementia in Europe" magazine, its monthly e-mail newsletter (reaching over 10,500 recipients), its [YouTube channel](#) and its social media presence on LinkedIn, Instagram, Facebook and X (Twitter),
- its Annual Conferences, which attract around 1000 participants a year and provide unique opportunities to network and present projects and research results.

## Criteria for involvement in research projects

Due to the great number of requests to join research projects and Alzheimer Europe's own limited staff and financial resources, Alzheimer Europe will prioritise projects that the organisation is meaningfully involved in. In order to evaluate its involvement in EU projects, the organisation needs a minimum of a week to discuss its contribution and budget. For that reason, requests to collaborate sent with less than a week before the call deadline will be declined automatically.

Alzheimer Europe is open to join additional projects as full project partners or to play a more limited role (for example on Advisory Boards) as long as the organisation's involvement is duly remunerated. This entails reimbursement for travel and accommodation of AE staff, and for the time required to prepare for and attend meetings. For public involvement activities with the European Working Group of People with Dementia, the European Dementia Carers Working Group, Public Involvement Pool, or representatives of national Alzheimer's associations, travel and accommodation costs of meeting participants, as well as the staff time for AE staff supporting or organising and writing up the consultation will also need to be reimbursed.

Alzheimer Europe will not write letters of support for research projects in which it has no meaningful involvement.