

## 2022 Work Plan and Budget

Adopted by the AE Board on 13 December 2021

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## **1 2022 Work Plan**

### **1.1 Alzheimer Europe Core activities**

#### **1.1.1 Objective 1: Providing a voice to people with dementia and their carers**

In 2022, Alzheimer Europe will

- involve the European Working Group of People affected by Dementia (EWGPWD) in its activities and organise two face-to-face meetings and a series of virtual meetings and consultations
- develop recommendations and the procedure to set up the European Carers Working Group (ECWP) and organise a first face-to-face meeting and virtual meetings and consultations
- develop a business model for the consultation of the EWGPWD and ECWP by commercial companies and academic researchers
- involve the EWGPWD and ECWP in the organisation of the Annual Conference by including representatives in the Programme Committee to help with the selection of abstracts, to deliver a keynote presentation each and organise two special symposia on the experience of people affected by dementia on the one hand and of their families and carers on the other
- involve the EWGPWD and ECWP in various EU projects where AE is asked to provide the views of people with dementia and their carers
- involve the Chairperson of the European Working Group of People with Dementia as a full voting member at AE Board meetings
- prepare a statutory amendment to allow the Chairperson of the ECWP to join the AE Board as an ex officio member
- continue its collaboration with the European Disability Forum and European Patients' Forum to ensure the views of people with dementia and their carers are included in EU policies and decisions

#### **1.1.2 Objective 2: Making dementia a European priority**

In 2022, Alzheimer Europe will

- carry out an overview of employment and social security rights of people with dementia and their carers and review their compliance with UNCRPD principles and dedicate its 2022 Dementia in Europe Yearbook to the topic
- develop the European Alzheimer's Alliance with the aim of gathering the support of 100 Members of the European Parliament from all European countries and involve members of the European Alzheimer's Alliance in the organisation of three lunch debates in the European Parliament
- campaign for the inclusion of dementia as a priority of the European Union's disability, health and research programmes
- collaborate with the French and Czech Presidencies and reach out to the Swedish and Spanish Presidencies of the Council of the European Union in collaboration with national member organisations to address dementia as Presidency priorities
- coordinate the group of European government experts on dementia and organise two meetings of the group bringing together health and social ministry officials from at least

15 countries with representatives from the European Commission, the OECD and the World Health Organization

- play an active role on the Patients' and Consumers' Working Party of the European Medicines Agency
- collaborate, as a member, with the European Patients' Forum and European Disability Forum and support the development of positions in response to EU policy developments

### **1.1.3 Objective 3: Changing perceptions and combating stigma**

In 2022, Alzheimer Europe will

- develop, in collaboration with the EWGPWD, a guide on the use of non-stigmatising, respectful and inclusive language when communicating about dementia and people with dementia
- set up the Board of the European Dementia Ethics Network with experts on ethics, law and people with lived experience with representation from at least 20 European countries
- continue its collaboration with the European Disability Forum on the European disability strategy and the implementation of the UN Convention on the Rights of Persons with Disabilities (UNCRPD)
- develop the procedure for the award of a prize for best European initiative addressing the stigma attached to dementia and changing public perceptions ensuring the full involvement and participation of national Alzheimer's associations
- continue working with the Council of Europe and contribute to ongoing discussions on legal capacity, guardianship systems and bioethics

### **1.1.4 Objective 4: Raising awareness of brain health and prevention**

In 2022, Alzheimer Europe will

- develop a position on how to disclose risk of developing dementia to asymptomatic persons or people with mild cognitive impairment
- identify phase II and phase III trials on the prevention of Alzheimer's disease and dementia and include them in the Clinical Trials Watch
- identify how to involve people at risk of developing dementia or with mild cognitive impairment through face-to-face panels or online consultation methods
- ensure the views of people at risk of developing dementia are included, when necessary, in European projects

### **1.1.5 Objective 5: Strengthening the European dementia movement**

In 2022, Alzheimer Europe will

- update its member organisations on relevant EU policy developments and involve them in the development of policy positions through AE's public affairs meetings
- organise its Alzheimer's Association Academy as a series of online workshops and develop a programme based on the subjects and issues identified by its members
- organise quarterly meetings of the AE Board to monitor the association's financial situation and the implementation of its work plan

- review the organisation's Statutes and Rules and Regulations and consult its members on procedures to change
- continue to partner with Newsweaver for the sending of its e-mail newsletter and aim to expand the list of people receiving the newsletter to 8,000 (with an open rate of 15%)
- continue the development of its website and aim to attract 750,000 unique visitors to its website
- ensure social media are a full part of the organisation's communication activities and aim to have 17,500 Twitter followers and Facebook likes by the end of the year.

#### **1.1.6 Objective 6: Supporting dementia research**

In 2022, Alzheimer Europe will

- continue with the development of its European Dementia Observatory by proactively identifying relevant research developments and communicating them to its member organisations and wider community
- update the working methods and membership of the organisation's Expert Advisory Panel
- organise a conference in Bucharest, Romania under the motto "Building bridges with the participation of at least 600 participants from 30 European countries"
- improve the collaboration with the INTERDEM network and the European Alzheimer's Disease Consortium for the organisation of the conference and the selection of topics to be addressed
- evaluate participants' satisfaction with the conference programme and practical organisation

### **1.2 Other activities and projects**

#### **1.2.1 EU Project participation**

In 2022, Alzheimer Europe will

- continue to engage with the Innovative Health Initiative, the Joint Programme Neurodegenerative Diseases Research (JPND), Horizon Europe and the European Innovation Partnership on Active and Healthy Ageing to identify additional opportunities to participate in EU projects,
- continue its active involvement in a number of EU funded projects by representing the views of people with dementia and their carers in the research consortium, by contributing to the ethical discussions and by supporting the communication and dissemination activities towards a non-scientific audience:
  - AI-MIND (Intelligent digital tools for screening of brain connectivity and dementia risk estimation in people affected by mild cognitive impairment)
  - AMYPAD (Amyloid imaging to prevent Alzheimer's disease)
  - EPND (European Platform for Neurodegenerative Diseases)
  - Euro-FINGERS: Multi-modal precision prevention toolbox for dementia in Alzheimer's disease

- LETHE (A personalized prediction and intervention model for early detection and reduction of risk factors causing dementia, based on explainable AI and distributed Machine Learning)
- NEURONET (Efficiently Networking European Neurodegeneration Research)
- PRODEMOS (Prevention of Dementia using Mobile phone Applications)
- RADAR-AD (Development and validation of technology enabled, quantitative and sensitive measures of functional decline in people with early stage Alzheimer's Disease)
- RECOGNISED (Retinal and cognitive dysfunction in type 2 diabetes: unravelling the common pathways and identification of patients at risk of dementia)
- VirtualBrainCloud (Personalized Recommendations for Neurodegenerative Disease)
- Continue its collaboration with the following research projects
  - ADAIR
  - DISTINCT
  - MIRIADE
  - SPAN+
- Start collaborating on the following research projects
  - ADIS (Early diagnosis of Alzheimer's disease by immune profiling of cytotoxic lymphocytes and recording of sleep disturbances)
  - Pattern-Cog (Personalised ageing pattern for early risk detection and prevention of cognitive impairment and dementia in cognitively healthy individuals)

### **1.2.2 Corporate Affairs**

In 2022, Alzheimer Europe will

- continue including phase II and phase III clinical trials being conducted in Europe on the AE website
- organise quarterly company round tables bringing together the AE Board, representatives of corporate sponsors and AE member organisations to discuss the progress of the organisation's different corporate projects
- organise an award ceremony for the most successful campaign or initiative to address the stigma attached to dementia and to change public perceptions about dementia
- bring together key representatives of European organisations with an interest in dementia for a European Dementia Summit to discuss common views on dementia research and policy
- publish three editions of the Dementia in Europe magazine (February, June and October)
- organise three lunch debates/workshops in the European Parliament in February, June and September.

### 1.3 Annex 1: 2022 Calendar

Date	Meeting	Venue
22 February	Alzheimer Europe Board	Online
22 March	European Parliament workshop	Online
23 March	Company Round Table	Online
24 March	Public Affairs Meeting	Online
4 April	Alzheimer Europe Board	Online
26 April	Alzheimer's Association Academy	Online
16 May	Alzheimer Europe Board	Online
13 June	Alzheimer Europe Annual General Meeting	Brussels, Belgium
14 June	Company Round Table	Brussels, Belgium
14 June	European Parliament lunch debate	Brussels, Belgium
14-15 June	European Group of Governmental Experts on Dementia	Brussels, Belgium
14-15 June	European Working Group of People with Dementia	Brussels, Belgium
12 July	Alzheimer's Association Academy	Online
26-27 September	Alzheimer Europe Board	Brussels, Belgium
27 September	European Parliament lunch debate	Brussels, Belgium
27 September	Company round table meeting	Brussels, Belgium
27-29 September	European Working Group of People with Dementia	Brussels, Belgium
28 September	European Dementia Summit	Brussels, Belgium
17-19 October	32 <sup>nd</sup> Alzheimer Europe Conference "Building bridges"	Bucharest, Romania
15 November	Alzheimer's Association Academy	Online
5 December	Alzheimer Europe Board	Online
6 December	Company Round Table	Online
12 December	Alzheimer's Association Academy	Online
13 December	European Group of Governmental Experts on Dementia	Online