Alzheimer Europe

Changing perceptions, policy and practice
to improve the lives of people affected by dementia

3O APRIL 2024, LUXINNOVATION WEBINAR

Collaborative engagement with patient organisations in EU-funded research

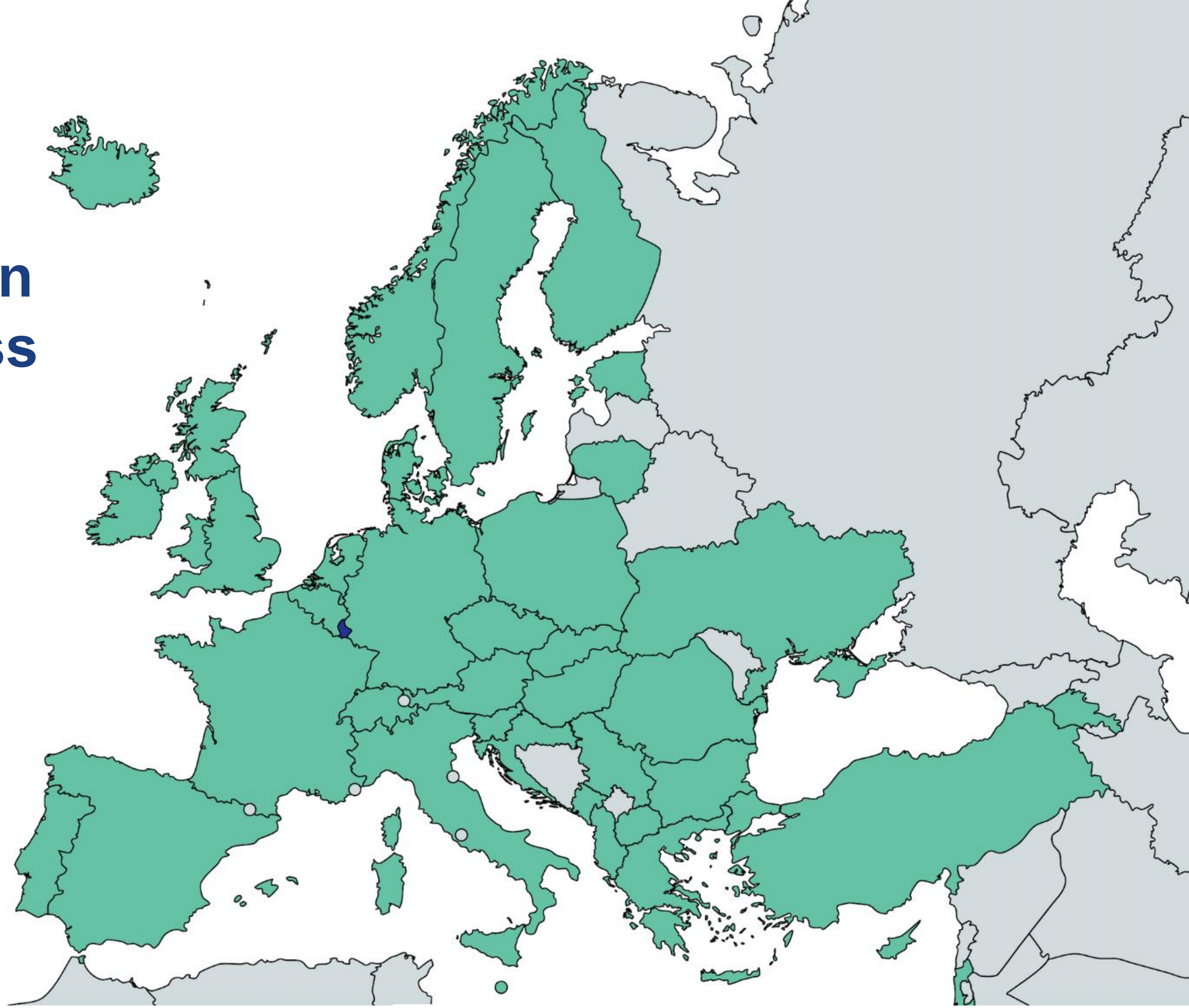
Angela Bradshaw, PhD

Director for Research, Alzheimer Europe

Ana Diaz, PhD

Public Involvement Lead, Alzheimer Europe

Alzheimer Europe is the umbrella organisation of 41 national Alzheimer's Associations across 37 countries



Providing a voice to people with dementia and their carers

- European Working Groups of People with Dementia, carers; public involvement work

Making dementia a European priority

- European Governmental Expert Group on Dementia, European Alzheimer's Alliance

Changing perceptions and combating stigma

- European Dementia Ethics Working Group & reports

Raising awareness of brain health and dementia prevention

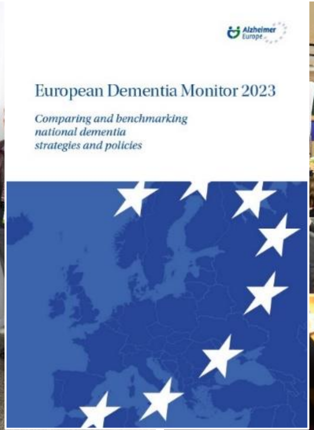
- Clinical trials watch with risk reduction studies; public involvement with at-risk indvs.

Strengthening the European dementia movement

- Public Affairs meetings with members, Alzheimer's Association Academy

Supporting dementia research

- Clinical trials watch; EMA, EADC, EAN & INTERDEM collaborations
- Participation in Horizon EU, IMI/IHI & JPND projects, annual conference #AEC



Alzheimer Europe

European Dementia Monitor 2023

Comparing and benchmarking national dementia strategies and policies

Meaningfully involve patients & caregivers

Patient-centered research & outcomes

Craft accessible communications

Increased credibility & acceptance

Leverage networks & real-world experience

Pathways to implementation & impact

Patient organisations in Europe – a diverse ecosystem

European Public Health Alliance (EPHA)

European Patients' Forum (EPF)

Alzheimer Europe

Association of European Cancer Leagues

Health Action International (HAI)

International Diabetes Federation (Europe)

Association of European Coeliac Societies (AOECH)

Digestive Cancers Europe

your voice for CAM in Brussels

EUROCAM

European Public Health Association (EUPHA)

European Respiratory Society (ERS)

Eurordis-Rare Diseases Europe

European AIDS Treatment Group (EATG)

European Alcohol Policy Alliance (Eurocare)

European Heart Network (EHN)

European Kidney Health Alliance

+ more!

+ national patient associations

AE participation in EU-funded research projects

Stakeholder engagement

Collaborative engagement with key societal, policy, research & clinical stakeholders in Europe

Public Involvement

Ensuring that research reflects the perspectives, needs & values of people affected by dementia

Communications

Leveraging AE or project-specific channels to communicate & raise awareness

Ethical & policy reflections

Discussing challenges for ethics, policy & practice

Alzheimer Europe

Public Involvement


Dianne Gove


Ana Diaz


Daphne Lamirel


Soraya M-Bachiller

Ethical & policy reflections


Owen Miller


Lukas Duffner

Communications


Cindy Birck


Chris Bintener

Stakeholder engagement


Sarah Campill


Jean Georges
Executive Director

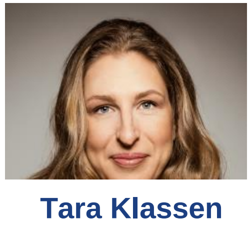

Stefanie Peulen


Kate Ellis


Gwladys Guillory


Cristina Pencea


Grazia Tomasini


Tara Klassen

Alzheimer Europe - research project areas

Alzheimer Europe

→ PLATFORMS FOR BRAIN RESEARCH

epnd European Platform for Neurodegenerative Diseases

eBRAIN-Health

→ AI FOR DETECTION, DIAGNOSIS AND CARE

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

→ DEMENTIA SCREENING, DIAGNOSIS & MANAGEMENT

AD-RIDDLE
Advancing Solutions for Alzheimer's Disease

Prominent
PRECISION MEDICINE
IN NEURODEGENERATION

→ DEMENTIA RISK REDUCTION & BRAIN HEALTH

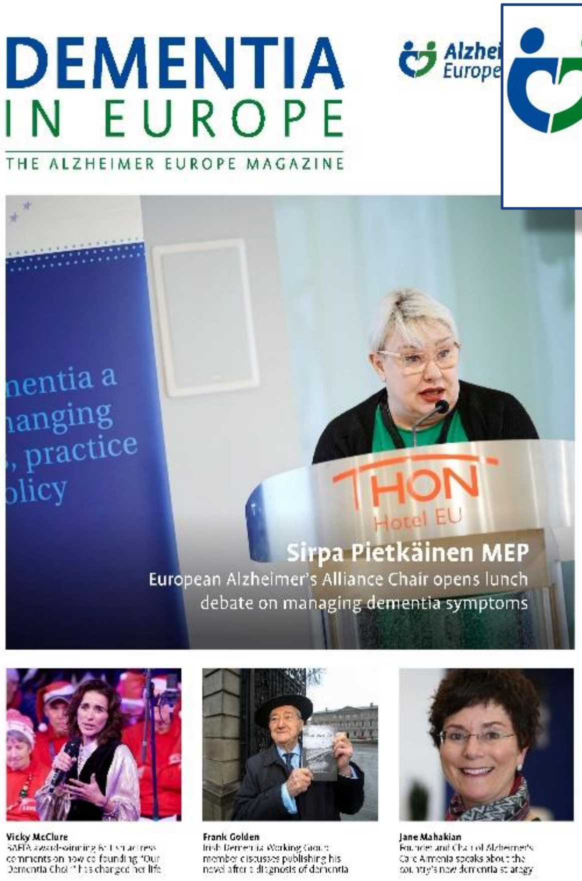
lethe

multi-memo

Stakeholder engagement

European Group of Governmental Experts on Dementia

National policymakers: representatives from ministries of health, social affairs and others



DEMENTIA IN EUROPE

THE ALZHEIMER EUROPE MAGAZINE

Sirpa Pietkäinen MEP

European Alzheimer's Alliance Chair opens lunch debate on managing dementia symptoms

Vicky McClure

BAFTA award-winning British actress comments on how co-founding "Our Dementia Choir" has changed her life

Frank Golden

Irish Dementia Working Group member discusses publishing his novel after a diagnosis of dementia

Jane Mahakian

Founder and Chair of Alzheimer's Care Armenia speaks about the country's new dementia strategy

European Alzheimer's Alliance

EU policymakers: 97 MEPs, from 26 countries, who have signed the Dementia Pledge

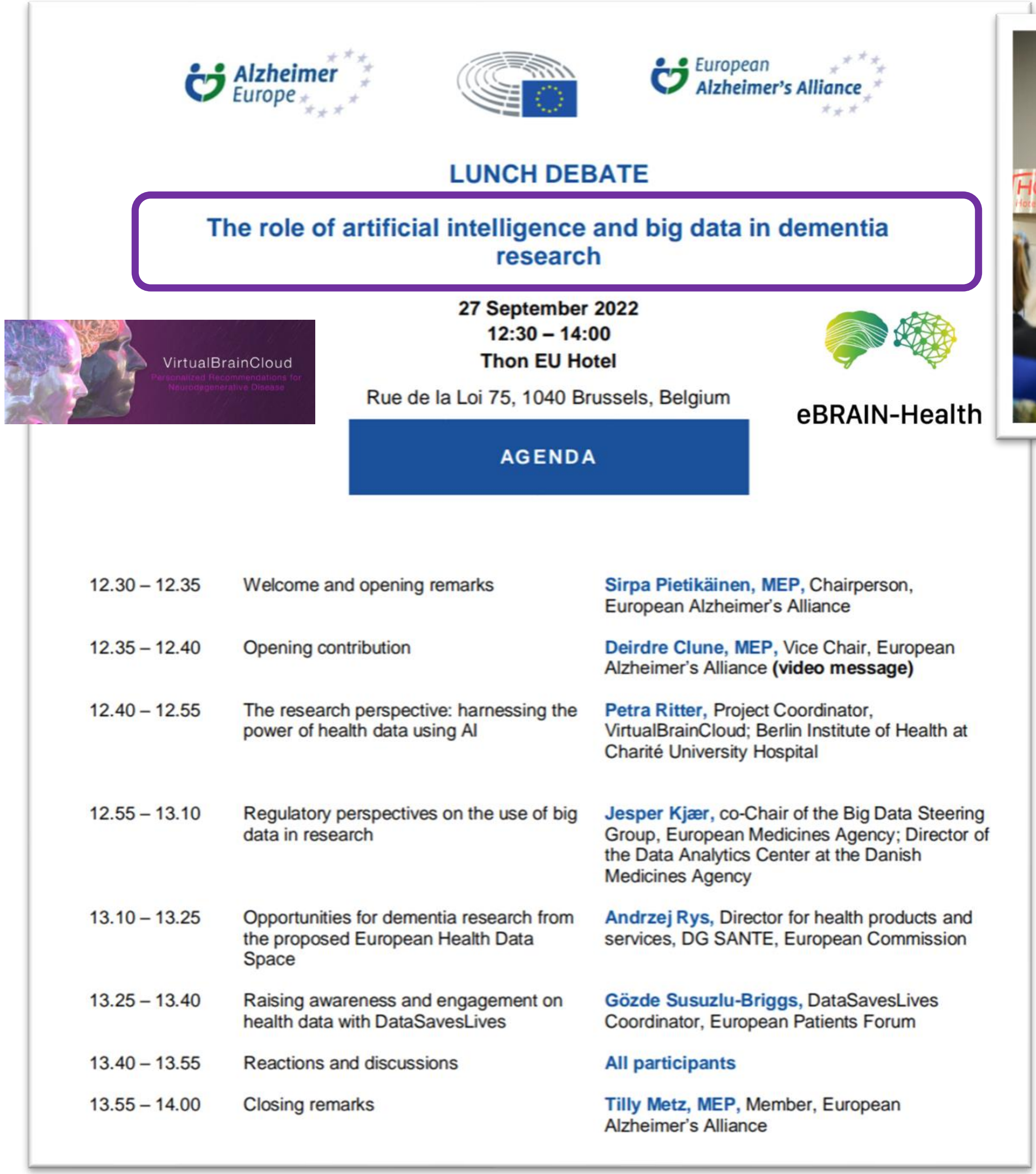
Alzheimer Europe Board and members

Representatives from 41 national Alzheimer Associations, from 37 countries

European Parliament meetings

Annual Conference #AEC

Annual Conference #AEC



LUNCH DEBATE

The role of artificial intelligence and big data in dementia research

27 September 2022
12:30 – 14:00
Thon EU Hotel
Rue de la Loi 75, 1040 Brussels, Belgium

AGENDA

12.30 – 12.35	Welcome and opening remarks	**Sirpa Pietikäinen, MEP,** Chairperson, European Alzheimer's Alliance
12.35 – 12.40	Opening contribution	**Deirdre Clune, MEP,** Vice Chair, European Alzheimer's Alliance **(video message)**
12.40 – 12.55	The research perspective: harnessing the power of health data using AI	**Petra Ritter,** Project Coordinator, VirtualBrainCloud; Berlin Institute of Health at Charité University Hospital
12.55 – 13.10	Regulatory perspectives on the use of big data in research	**Jesper Kjær,** co-Chair of the Big Data Steering Group, European Medicines Agency; Director of the Data Analytics Center at the Danish Medicines Agency
13.10 – 13.25	Opportunities for dementia research from the proposed European Health Data Space	**Andrzej Rys,** Director for health products and services, DG SANTE, European Commission
13.25 – 13.40	Raising awareness and engagement on health data with DataSavesLives	**Gözde Susuzlu-Briggs,** DataSavesLives Coordinator, European Patients Forum
13.40 – 13.55	Reactions and discussions	**All participants**
13.55 – 14.00	Closing remarks	**Tilly Metz, MEP,** Member, European Alzheimer's Alliance

European Alzheimer's Alliance of MEPs

Research project leader

EMA representative

European Commission representative

Civil society organisation

PUBLIC INVOLVEMENT IN DEMENTIA RESEARCH

ANA DIAZ, PUBLIC INVOLVEMENT LEAD

What is Public Involvement (PI) …?

→ Public Involvement is about research carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them.

→ It typically involves members of the public (e.g. people affected by or with an interest in dementia) working together with researchers and sharing their perspectives, experiences, and needs regarding the research topic, design, and conduct of the study.

→ Many important reasons to do PI, among others, it can:

- improve the research process and outcomes (e.g. quality, relevance, utility of research)
- provide knowledge that might otherwise be missing drawing on personal experience and views (the “lived” experience”)
- gives voice to people about research which is relevant to them and their lives

Alzheimer Europe's approach

→ AE's work on PI started in 2012 with our European Working Group of People with Dementia. We recently set up the European Dementia Carers Working Group and several project-specific Advisory Boards.

→ Our model has been developed over the years. Some of the main principles are:

- Activities have to be carefully planned, timely and meaningful to everyone involved.
- Diversity (instead of representation).
- Adapt and accommodate to individual interests, preferences and abilities.
- Provide appropriate support when needed.
- Build & maintain mutually respectful relationships between people with dementia and researchers.

Some examples: EU-FINGERS and MULTI-MeMo project

Alzheimer Europe

EU-FINGERS®
EUROPEAN MULTIDOMAIN INTERVENTIONS
FOR DEMENTIA PREVENTION

multi-
memo

- Funded by JPND, FNR in Luxembourg
- Under the “FINGER umbrella” working on dementia risk reduction.
- Members of the AB are from different countries (Finland, Sweden, Spain, UK, Netherlands, Hungary, Luxembourg), and include people with and without dementia.
- Regular meetings (online and in person).
- Support, reciprocity and respect.
- Joining efforts and leveraging existing work.

Luxembourg
National
Research Fund

JPND
research
EU Joint Programme – Neurodegenerative Disease Research

How can PI influence research, the people involved and the researchers?

We conduct consultations where members provide advice or have discussions on different topics which are very important for the researchers, for example:

- Terms and terminology: prevention, risk reduction, brain health …
- Review of participant-facing materials in the study (e.g. participant information sheet, consent form)
- Feedback and advise about technology to be used in the study
- Discussion on ethical and social implications of the study.

It is also important for members and researchers

- To members: it brings hope, trust, value, meaning, joy …
- To researchers:

https://www.youtube.com/clip/UgkxtZvsiTlCIYSXs7yw1IpuGLn0jmd1lKnU

Some resources

→ Articles and publications

https://www.alzheimer-europe.org/research/public-involvement

→ Videos

https://www.youtube.com/channel/UClfvnXpZRXorC3bdX8q0ZiA

JPND research
EU Joint Programme – Neurodegenerative Disease Research

Luxembourg National Research Fund

EU-FINGERS and Multi-MeMo are EU Joint Programme - Neurodegenerative Disease Research (JPND) projects and are supported by the Luxembourg national research fund (FNR

Please sign our **Call to Action**, to ask EU policymakers to make dementia a priority!

Thankyou!