

# Involving research participants in research: The example of the EPAD (European Prevention of Alzheimer's Dementia) project

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Alzheimer Europe Annual Conference  
Barcelona 2018

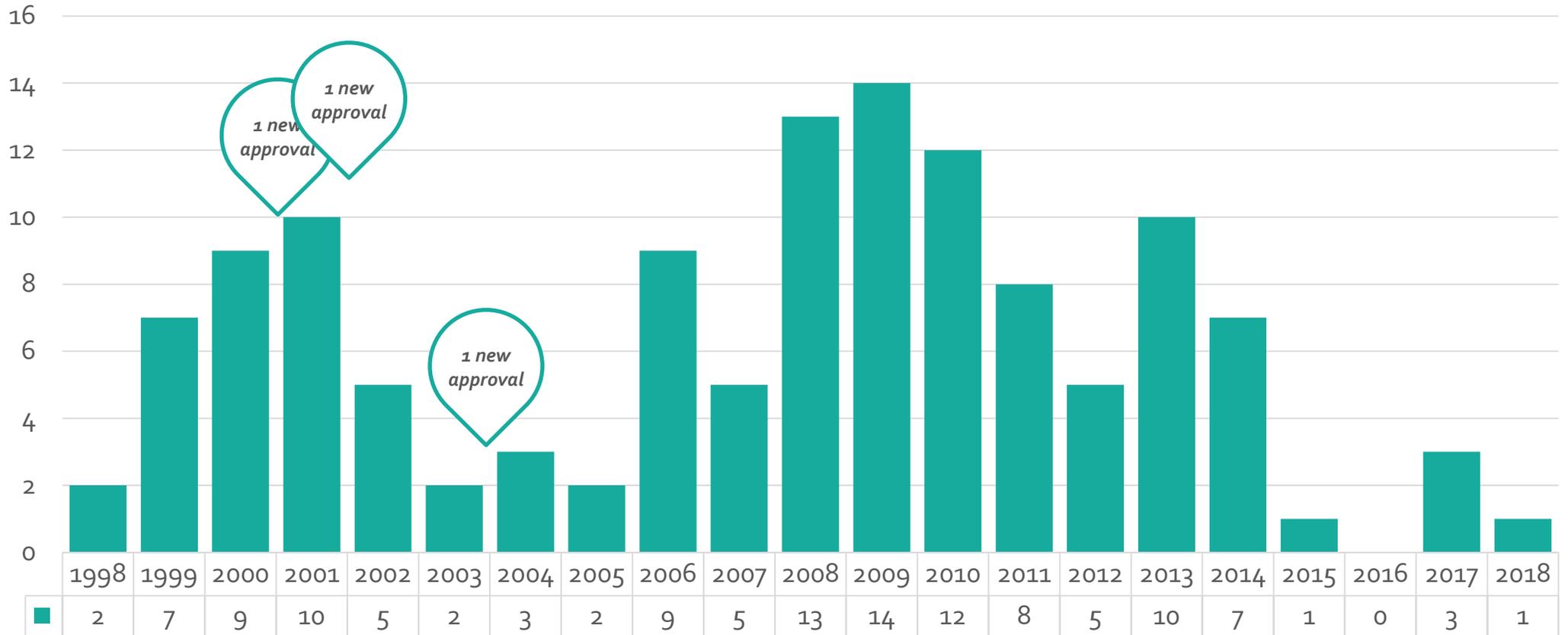


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## Unsuccessful investigational drugs for Alzheimer's disease 1998–2018

Number of  
Alzheimer's disease drugs  
no longer under  
development



**4 total approved medicines**

# The European Prevention of Alzheimer's Dementia (EPAD)



EPAD is one of the biggest Alzheimer's dementia studies in the world

A €64 million private-public partnership with 38 partnering organisations and 21 sites running the EPAD study across Europe

**Longitudinal Cohort Study**



**Drug trial**

Currently over 1000 active participants  
This study forms the readiness cohort for the drug trial

Drug trials for Phase II clinical studies with people with preclinical and prodromal Alzheimer's disease.

# EPAD study involvement

## Phone call:

chatting to the research team on the phone and asking questions about the study



On a separate day, participants come back for a **lumbar puncture** (spinal fluid sample)

**Cognitive assessments** (memory, attention (s))

**These visits are repeated annually**

As part of the assessments we take **biological samples**. We take a blood sample, saliva sample and a urine sample



Breakfast

Seeing the **study doctor** (we take participants' medical history, note down any medications and perform a medical check such as ECG and blood pressure)

Break

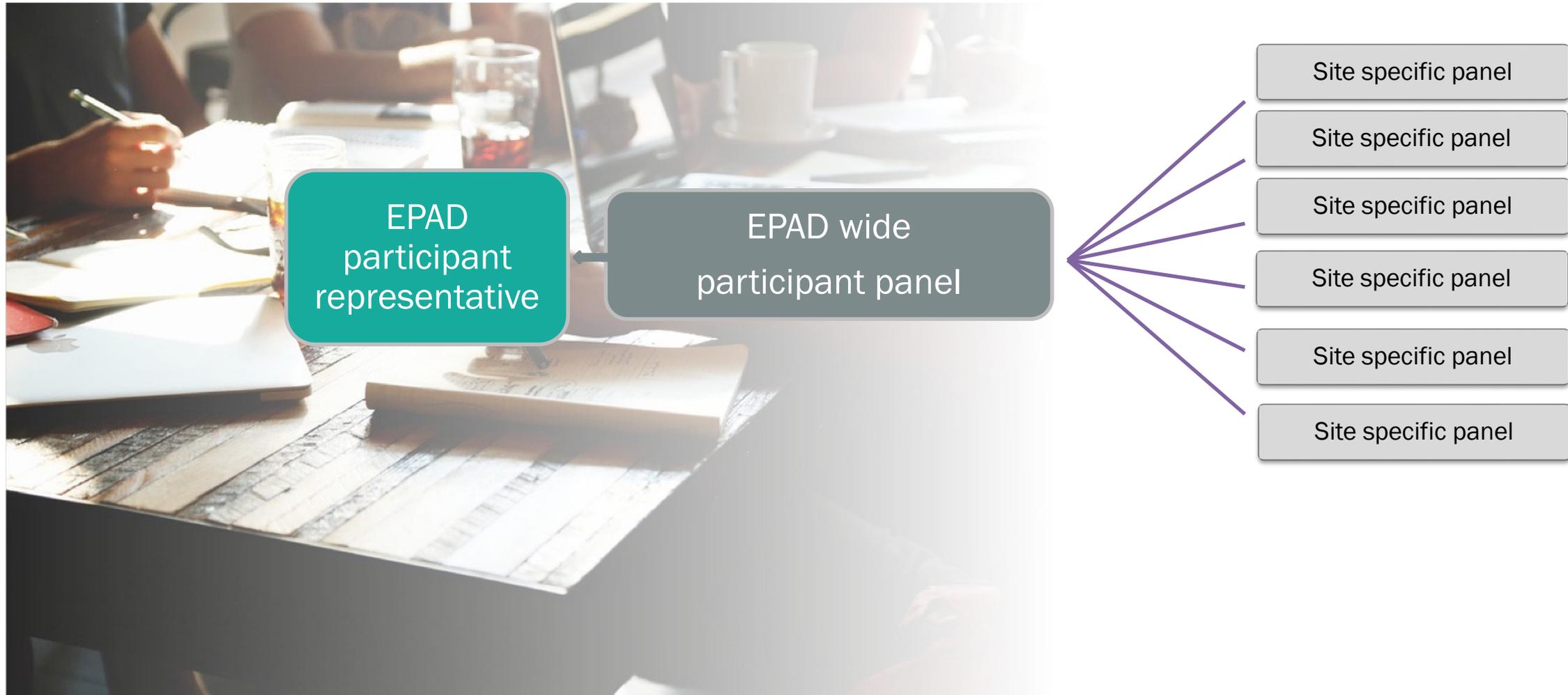


# Aim of the Participant panel

- **Provide feedback** on good and bad elements of study experience and **recommendations for improvements**
- Ensure that participants are represented in **decision making** which may affect them such as sub-studies or study logistics
- **Review documents** related to the study aimed at participants such as Information Sheets or Recruitment flyers
- Work with the EPAD team to **communicate about the study** at national and international conferences



# How does the panel work?



# Why is EPAD involving participants?

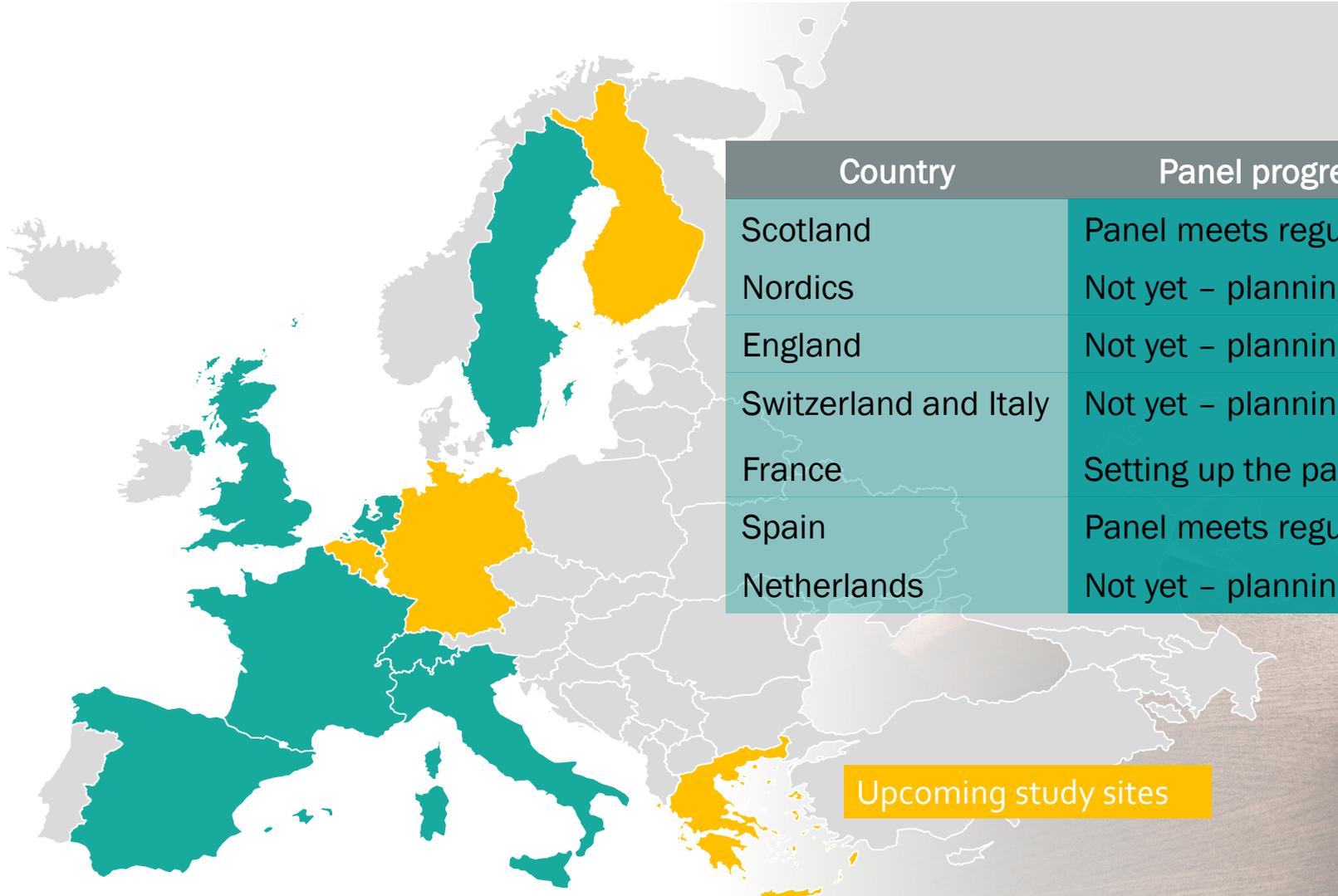
Research participant

Collaborator

- Recognise **the value of the participants' contributions** to the project
- Bring on board **retention ideas** from participants
- Ensure the **participant perspectives** are heard and incorporated into the study
- **Address any issues directly** which may affect future study involvement (e.g. logistics)
- **Improve study documents** and **website** with feed back



# Participant panels so far across the EPAD study



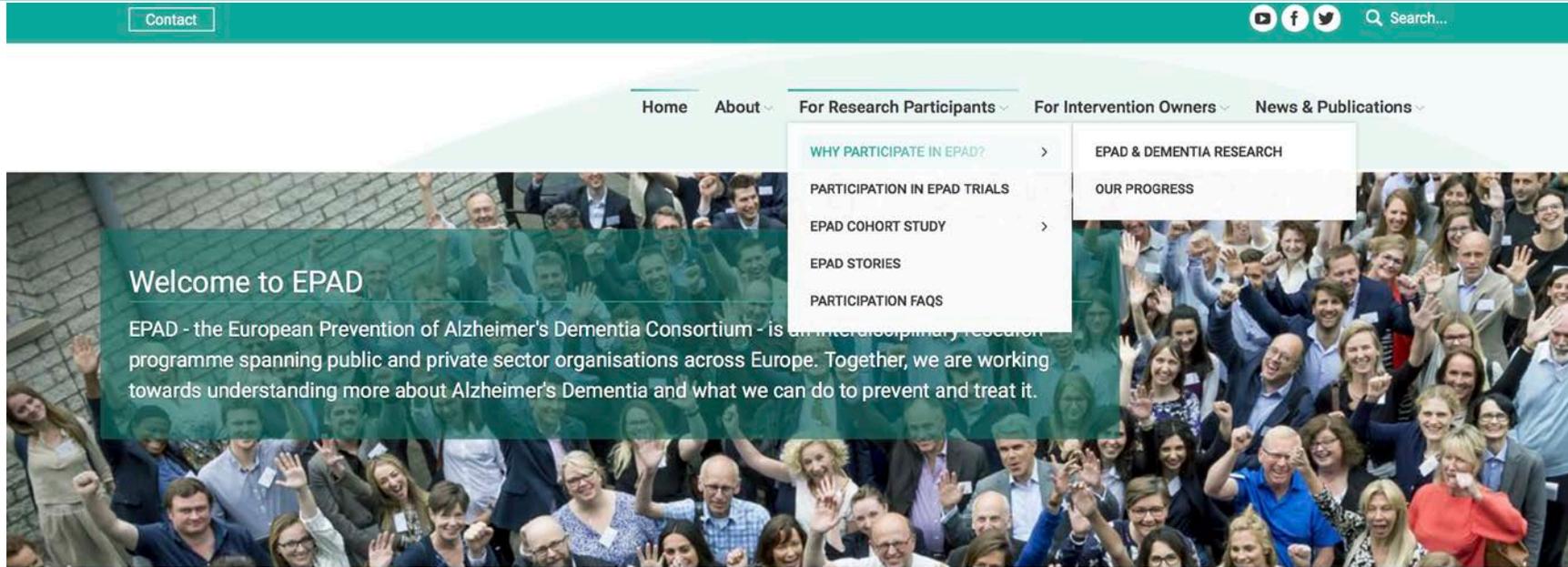
Country	Panel progress
Scotland	Panel meets regularly
Nordics	Not yet – planning stage
England	Not yet – planning stage
Switzerland and Italy	Not yet – planning stage
France	Setting up the panel
Spain	Panel meets regularly
Netherlands	Not yet – planning stage

Upcoming study sites



Updated 15 September 18

# EPAD Edinburgh Participant Panel



The screenshot shows the EPAD website's home page. At the top, there is a teal navigation bar with a 'Contact' button, social media icons for YouTube, Facebook, and Twitter, and a search bar. Below the navigation bar, a main menu includes 'Home', 'About', 'For Research Participants', 'For Intervention Owners', and 'News & Publications'. The 'For Research Participants' menu is open, showing options like 'WHY PARTICIPATE IN EPAD?', 'PARTICIPATION IN EPAD TRIALS', 'EPAD COHORT STUDY', 'EPAD STORIES', and 'PARTICIPATION FAQS'. A secondary menu for 'EPAD & DEMENTIA RESEARCH' is also visible, with 'OUR PROGRESS' selected. The main content area features a large image of a diverse group of people waving, with a semi-transparent teal box overlaid. The text in the box reads: 'Welcome to EPAD. EPAD - the European Prevention of Alzheimer's Dementia Consortium - is an interdisciplinary research programme spanning public and private sector organisations across Europe. Together, we are working towards understanding more about Alzheimer's Dementia and what we can do to prevent and treat it.'



  
**38**  
Partnering Organizations

  
**20**  
Study Sites

  
**1,077**

## Latest News

EPAD WP6 team reviews communication strategy and makes plan for 2019

2018-10-05

Our epadistas organised several events to mark World Alzheimer's Day

2018-09-28

The first EPAD Academy short exchange program has started

2018-09-24

# EPAD Edinburgh Participant Panel

Item	Acronym	Definition	Explanation
2	AAIC	Alzheimers Association International Conference	Big annual conference around Alzheimer's disease
3	ACCORD	Academic and Clinical Central Office for Research and Development	University of Edinburgh and NHS joint office to facilitate clinical research
4	AD	Alzheimer's Disease	
5	ADL	Activities of Daily Living	Driving, cooking, cleaning, handling money
6	ADNet	Australian Dementia Network	
7	ADNI	Alzheimer's Disease Neuroimaging Initiative	
8	AE	Adverse Event	Unfavourable and unintended event that may occur during a drug trial
9	AMYPAD	Amyloid Prevention of Alzheimer's Dementia	Sub-study of EPAD which involves undergoing PET imaging
10	APOE	Apolipoprotein E	A gene. A certain type (APOE-ε4) is associated with Alzheimer's disease
11	AWI	Adults with Incapacity	Adults who are not able to make legal decisions for themselves
12	BC	Balancing Committee	
13	BISQ	Brain Injury Screening Questionnaire	Questionnaire about any traumas suffered to the head
14	BMI	Body Mass Index	A score derived from the weight and height of an individual
15	CCSC	Clinical Candidate Selection Committee	
16	CDR	Clinical Dementia Rating	An assessment measure used to measure how well a patient's memory is functioning
17	CI	Chief/Coordinating Investigator	Lead researcher of the study
18	CSF	Cerebrospinal fluid	Water like fluid found in the brain and spinal cord
19	CTAD	Clinical Trials on Alzheimer's Disease	Big annual conference around clinical trials Alzheimer's disease
20	CTIMP	Clinical Trial of Investigational Medicinal Product	Clinical trial
21	DAEM	Detecting Alzheimers & Enhancing Memory	
22	DOC	Data Oversight Committee	
23	DSMB	Data Safety Monitoring Board	
24	EBM	Event Based Modelling	
25	ECG	Electrocardiogram	A test to check a heart's rhythm and electrical activity
26	ELSI	Ethical Legal Social Implications	Work stream focusing on the ethical, legal and social implications around Alzheimer's
27	EMA	European Medicines Agency	An organisation to evaluate and approve medicinal products
28	ENE	EPAD Neuropsychological Examination	Thinking and memory tasks undertaken in the EPAD study
29	EPAD	European Prevention of Alzheimer's Dementia	EPAD study
30	GA	General Assembly	Annual meeting with all the EPAD researchers and some participant representatives
31	GCP	Good Clinical Practice	A code of conduct for doing clinical research
32	GDPR	General Data Protection Regulations	Rules all researchers follow when managing research participants personal data
33	ICF	Informed Consent Form	Consent form signed at the beginning of the study



- Participant panel **representatives are present** at the General Assembly
- Idea is to **learn about project** and feed back to fellow participants at home
- **Offer insight into what it is like to take part in EPAD** as a study participant to the consortium and members who work on EPAD but have no contact with participants
- Participants collaborating with researchers **as equal partners**



# Key messages

- EPAD is a globally important study aimed to prevent Alzheimer's dementia
- **Participant's voice vital to the success of the study**
- Participant panel is the solution for incorporating the participant perspective



# Acknowledgements

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# EPAD

European Prevention of  
Alzheimer's Dementia Consortium



efpia



# Thank you!

Gregory, S., Wells, K., Forsyth, K., Latto, C., Szyra, H., Saunders, S., Ritchie, C.W., Milne, R. (2018). Research participants as collaborators: Background, Experience and Policies from the PREVENT Dementia and EPAD Programmes. *Dementia*

 [ep-ad.org](http://ep-ad.org) – subscribe to EPAD newsletter

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