

# The EPAD Participant Panel

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## Background & aims

- EPAD (European Prevention of Alzheimer’s Dementia) is a major European project led from Scotland. Initiated in 2014 it is recruiting a cohort of participants across the **’at-risk for dementia’** spectrum<sup>1</sup>.
- **Active participant involvement** has been clearly recognised as being a key factor to ensure the **success** of the project from it’s initiation, building on the success of the PREVENT Participant Panel<sup>2</sup>.
- The EPAD Participant Panel (Scotland) is seen as a **significant mechanism** for directly involving and retaining participants **throughout the various EPAD project phases** from Longitudinal Cohort Study to Proof-of-Concept trial.

## Set up and design of the panel

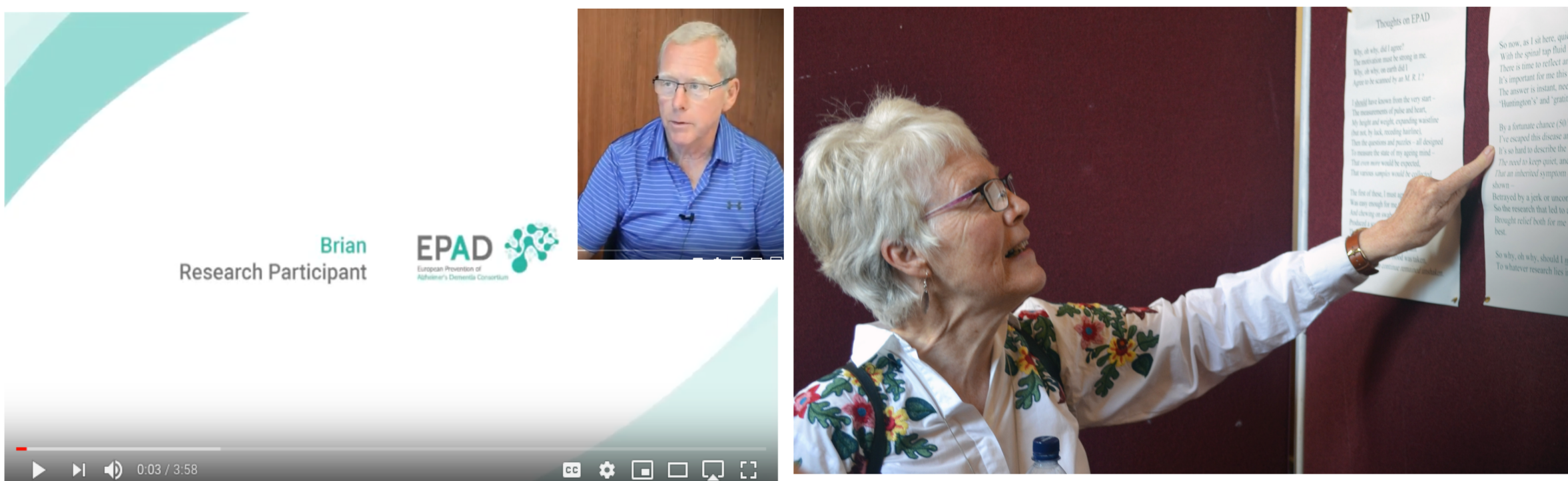
- The Edinburgh EPAD Participant Panel was first established in March 2017 in Edinburgh, consisting of 8 members and is **chaired by a participant**.
- **Panel members set the meeting agenda** and are supported supported by EPAD project staff who organise the logistics, record minutes, provide EPAD project updates and effectively communicate **panel feedback** to appropriate EPAD project team members to enact improvements. All panel members and EPAD staff are **working to achieve a common goal**.
- To date 4 panel meetings have been held (March & September 2017; April & September 2018), and the panel is **transitioning** from solely representing Edinburgh to becoming a **Scotland-wide panel**. Currently members from 2 Scottish centres are represented on the panel with a plan to have all **4 Scottish centres represented** by March 2019.

## Panel Roles and Responsibilities

- Provide **feedback and improvement recommendations** based on their own EPAD study experiences, including: lumbar puncture, MRI and cognitive testing.
- Act as a **conduit to receive, critique and further communicate** EPAD project information.
- Participate in the **development of EPAD documentation** such as a newly developed acronym list and participant experience videos.
- **Attend and present** at **national** (Aberdeen 2018) and **international** (Stockholm 2017, Amsterdam 2018) EPAD meetings to provide a participant perspective.
- Identify and work on **key focus areas** such as establishing better means to effectively communicate with participants not on the panel.

EPAD Acronyms (Rev: 20/09/18)

Item	Acronym	Description
1	EPAD	European Prevention of Alzheimer's Dementia
2	AD	Alzheimer's Disease
3	LCS	Longitudinal Cohort Study
4	TDC	Trial Delivery Centre
5	PPGS	Participant Panel Group Study
6	POC	Proof Of Concept



Examples of panel involvement in EPAD activities

## Conclusions and learning points

- The EPAD Participant Panel provides a **strong voice** to advocate on behalf of fellow participants. The panel is a valuable source of information in addressing crucial aspects of **participant experience, retention of participants** and is an avenue for a **meaningful engagement** for participants as important **partners** in the project.
- A participant panel has also been **established in Barcelona** with similar positive outcomes, work is ongoing to create new panels in other European countries as the EPAD project develops and expands.
- Establishing clear **terms of reference** and **common goals** has kept the panel aligned to the aims. Encouraging **active participation** and nominating a participant to the chair places the participant voice at the heart of the panel with EPAD staff providing **vital support** to ensuring matters arising are followed up in a timely manner.

*“We want thus to stand with the young academics and researchers helping to find a cure or amelioration for [Alzheimer’s Dementia]” Participant Panel Member*

References: 1. Ritchie et al, 2015, Development of interventions for the secondary prevention of Alzheimer’s dementia: the European Prevention of Alzheimer’s Dementia (EPAD) project; 2. Gregory et al, in press, Research Participants as Collaborators: Background Experience and Policies from the PREVENT Dementia and EPAD Programmes

