



# Involving research participants in a pan-European research initiative: the EPAD participant panel experience

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**Background:** Including participants in patient and public involvement activities is increasingly acknowledged as a key pillar of successful research activity. Such activities can influence recruitment and retention, as well as researcher experience and contribute to decision making in research studies. However, there are few established methodologies of how to set up and manage participant involvement activities. Further, there is little discussion of how to do so when dealing with collaborative projects that run across countries and operate in multiple linguistic and regulatory contexts.

**Methods:** In this paper we describe the set-up, running and experiences of the EPAD participant panel. The EPAD study was a pan-European cohort study with the aim to understand risks for developing Alzheimer's disease and build a readiness cohort for Phase 2 clinical trials. Due to the longitudinal nature of this study, combined with the enrolment of healthy volunteers and those with mild cognitive impairments, the EPAD team highlighted participant involvement as crucial to the success of this project. The EPAD project employed a nested model, with local panels meeting in England, France, Scotland, Spain and The Netherlands, and feeding into a central study panel. The local panels were governed by terms of reference which were adaptable to local needs.

**Results:** The impact of the panels has been widespread, and varies from feedback on documentation, to supporting with design of media materials and representation of the project at national and international meetings.

**Conclusions:** The EPAD panels have contributed to the success of the project and the model established is easily transferable to other disease areas investigating healthy or at-risk populations.

## Research Involvement and Engagement

Published **Online**

15 October 2020

<https://doi.org/10.1186/s40900-020-00236-z>

