



Research participants as collaborators: Background, experience and policies from the PREVENT Dementia and EPAD programmes

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Aim: Despite the growing importance of public and patient involvement in biomedical research, comparatively little attention has been paid to the important role of research participants themselves. Our aim in this paper is to explore the impact research participant involvement has within the PREVENT and the European Prevention of Alzheimer's Dementia (EPAD) projects.

Method: In this paper, we report the experiences of involving research participants as collaborators in prospective cohort studies exploring early changes in the brain as pathways towards and risks for dementia. We use minutes and feedback from members of the panel and steering committee to understand the experience and impact on the study.

Results: We describe the aims and structure of the participant panel established within the PREVENT Dementia study and highlight its contributions to the organisation, conduct and future of the study. Key areas of contribution identified include recruitment, inclusion of additional sub-studies, understanding the participant experience and contributing to the future of the study.

Discussion: We then describe how the PREVENT Dementia panel forms the basis for participant involvement within EPAD project.

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