EPAD Registry to facilitate recruitment into the cohort study and Alzheimer prevention trials

Lisa Vermunt1, Pieter Jelle Visser1,2, Lea ter Meulen1, Sandra Pla3, Carlos Diaz3, Iva Knezevic1, Craig Ritchie4, Gerald Luscan5, Colin Veal5, Vagelis Ladasa6, Dhiwagaran Thangavelua6, Anthony J Brookes6
1. VU Medical Center; 2 Maastricht University; 3 Synapse; 4 University of Edinburgh; 5 Pfizer; 6 University of Leicester. Special thanks to all collaborating cohorts and WP3 contacts within EPAD

Facts & Figures

| Start date: | 1/1/2015 |
| End date: | 31/12/2019 |

Contributions

| IMI funding: | 25 880 000 € |
| EFPIA in kind: | 27 160 286 € |
| Other: | 6 431 736 € |
| Total Cost: | 59 472 022 € |
| Project website: | www.ep-ad.org |
| Social media: | @IMI_EPAD |

Challenge

Set up an European Registry based on existing cohorts to face the recruitment challenge for clinical trials for the secondary prevention of Alzheimer’s Disease

Approach & Methodology

Step 1. Selection of cohorts

- Cohort A: Memory clinic-based cohort
- Cohort B: Population-Based cohort
- Cohort C: Cohort of selected population

EPAD Registry N = 20,000
Longitudinal Cohort Study (LCS) N = 1,000
Proof of Concept trial N = 5,000

Step 2 Data discovery approach

- Cohort A: Harmonized dataset
- Cohort B: Harmonized dataset

“PREPAD” Central
PREPAD administrator conducts searches

IDs

Step 3 Search fields for selection

- Demographics: Age, gender, education
- Cognitive: diagnosis, MMSE (change), immediate and delayed recall
- Risk factors and biomarkers: Apoe genotype, family history of Alzheimer, amyloid and tau biomarkers, MRI visual rating

Step 4 Implementation of collaboration

- An interface was adapted for EPAD usage
- Software was created to create encrypted IDs that are used to assure anonymity, but enable re-identification of participants by the collaborating cohorts

- After the appropriate contracts are signed, participants are invited by the collaborating cohorts

Results

Thirteen cohorts from France, Italy, the Netherlands, Sweden, Spain, Switzerland and the UK are currently linked to PREPAD, providing access to roughly 17,000 potential participants aged over 50 and without dementia (Table 1 and 2).

Over 3000 participants have been selected from 10 different cohorts of whom thus far around 12% agreed to participate.

Value of IMI collaboration

Essential for starting this novel approach and setting up the collaboration between the informatics and dementia researchers.

Impact & take home message

The EPAD registry was able to select participants from ongoing studies for the EPAD cohort study.

The use of existing data for selection of participants via a virtual registry could now be applied in other projects.

The effectiveness of the approach will depend on the phenotypical data available in cohorts and the level of engagement of the participants in these cohorts.

This work has received support from the EU/EFPIA Innovative Medicines Initiative Joint Undertaking EPAD grant no 115736.