10 YEARS OF BREAKTHROUGHS A HEALTHIER FUTURE

EPAD
European Prevention of Alzheimer's Dementia Consortium

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

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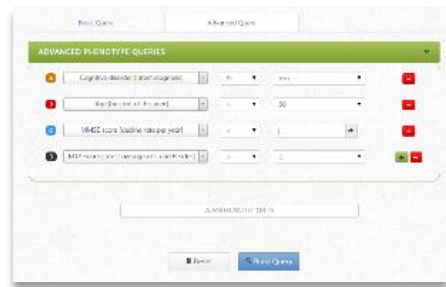
1. VU Medical Center; 2 Maastricht University; 3 Synapse; 4 University of Edinburgh; 5 Pfizer; 6 University of Leicester. Special thanks to all collaborating cohorts and WP3 contacts within EPAD

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
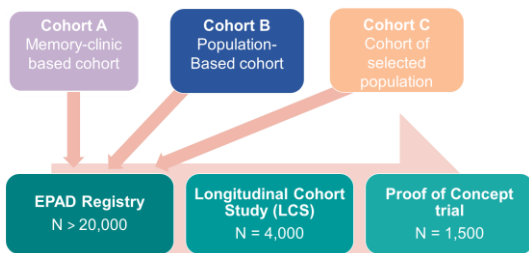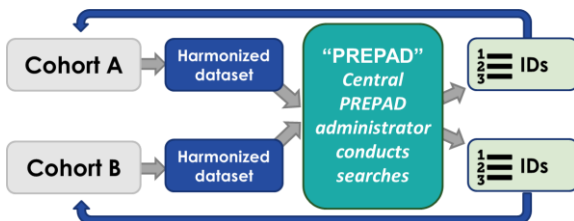
Step 1. Selection of cohorts

Figure 1. Different types of existing cohorts supply participants for the cohort through the EPAD Registry. Participants for the trial will in turn be selected from the cohort.

Step 2 Data discovery approach

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 particpate.

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.