



Short Report

European Prevention of Alzheimer's Dementia Registry: Recruitment and prescreening approach for a longitudinal cohort and prevention trials

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Abstract

Background: It is a challenge to find participants for Alzheimer's disease (AD) prevention trials within a short period of time. The European Prevention of Alzheimer's Dementia Registry aims to facilitate recruitment by preselecting subjects from ongoing cohort studies. This article introduces this novel approach.

Methods: A virtual registry, with access to risk factors and biomarkers for AD through minimal data sets of ongoing cohort studies, was set up.

Results: To date, ten cohorts have been included in the European Prevention of Alzheimer's Dementia Registry. Around 2500 participants have been selected, using variables associated with the risk for AD. Of these, 15% were already recruited in the European Prevention of Alzheimer's Dementia longitudinal cohort study, which serve as a trial readiness cohort.

The authors have declared that no conflict of interest exists.

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Discussion: This study demonstrates that a virtual registry can be used for the preselection of participants for AD studies.

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Keywords:

Preclinical AD; Prodromal AD; Clinical trial; Participant recruitment; Research registry; EPAD

1. Introduction

1.1. Finding participants for secondary prevention of Alzheimer's disease

Finding participants for Alzheimer's disease (AD) trials is challenging [1]. This is particularly the case for studies with prodromal or preclinical AD participants because these persons may not seek care for their problems and are unaware of the presence of amyloid pathology. An increasing number of AD trials aims to delay the onset of dementia in prodromal and preclinical AD. Traditional ad hoc recruitment strategies, such as advertising in newspapers, result in a costly, labor-intensive and long recruitment process with many screen failures. Novel preselection and patient recruitment strategies are warranted. Online registries or the use of existing data sources may help to facilitate recruitment [2]. European Prevention of Alzheimer's Dementia (EPAD) Registry makes use of existing data sources for recruitment in a virtual registry to speed up recruitment, reduce recruitment efforts, and reduce screen failures.

1.2. EPAD Registry as part of the EPAD project

The EPAD Registry is part of the European Prevention of Alzheimer's Dementia project. This project is meant to create a platform for AD secondary prevention trials and to improve the understanding of the development of AD,

by setting up the EPAD Registry, EPAD longitudinal cohort study (EPAD-LCS), and EPAD proof-of-concept (EPAD-PoC) trials [3]. The EPAD Registry was setup to find participants without dementia for the EPAD-LCS. In the EPAD-LCS, participants undergo longitudinal assessments of cerebral spinal fluid, blood, magnetic resonance imaging, AD risk factors, and cognition. The primary outcome is the Repeatable Battery for the Assessment of Neuropsychological Status. The EPAD-LCS serves as the trial readiness cohort for EPAD-PoCs. The first EPAD-PoC is planned to start in 2018.

The EPAD Registry preselects participants from ongoing cohort studies and uses data from these cohorts for prescreening. The EPAD Registry involves several steps (Fig. 1). First, the collaboration with an ongoing cohort study representative is established. Second, a minimal data set from the ongoing cohort study is created that can be queried in a software tool called PREPAD. Potential participants are identified and invited for the EPAD-LCS by the EPAD study team. The results of these efforts are monitored.

2. Methods

2.1. Selection of and engagement with ongoing cohort studies

Cohorts that are selected for the EPAD Registry fulfill the following criteria: they are willing to provide participants for

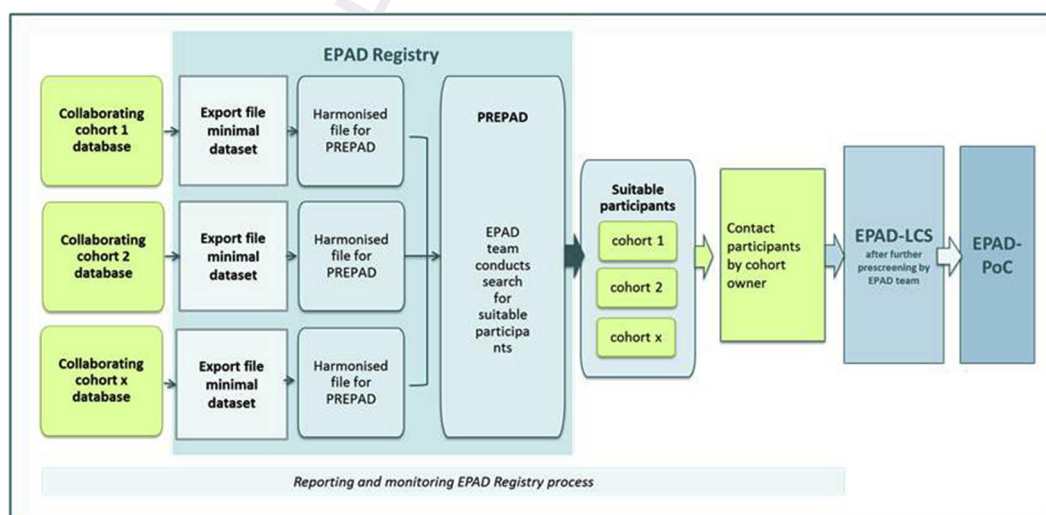


Fig. 1. Schematic overview of data and participant flow in EPAD. Abbreviations: EPAD, European Prevention of Alzheimer's Dementia; EPAD-LCS, EPAD longitudinal cohort study; EPAD-PoC, EPAD proof-of-concept trials.

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