

Executive Summary

The EPAD Register provides a novel way of recruiting participants into studies and clinical trials, by selecting suitable individuals from existing parent cohorts (henceforth: PCs). This selection is done by means of remotely, safely and anonymously querying subject data for demographics, risk factors, cognitive markers and biomarkers.

In the course of the project, the need was recognized for an additional alternative recruitment route to enable TDCs to directly recruit certain high-value participants, irrespective of whether or not they are in a PC. We have successfully developed and implemented this system, PREPAD Velocity, over the past months (Chapter 2). A monitoring system was brought into use to track the flow of participants registered through Velocity.

Velocity and the PREPAD subject discovery software constitute complementary approaches, and in the past year our core business of interacting with and informing PCs has continued (Chapter 5). Two new cohorts have been added to the Register and seven others, totalling over 13,000 potential participants, are currently in the process of getting connected. Five cohorts that were previously connected have added extra data variables and/or participants, with the latter extending our geographical reach. Over the same period, 2,491 potential participants were drawn from the Register for pre-screening for the EPAD Longitudinal Cohort Study (LCS). The process through which participants are selected relies on a close collaboration between different parties, described in detail in Chapter 4.

To evaluate the effectiveness of the Register, it is crucial to gather information on the parameters that influence the recruitment and retention of participants in the LCS, and the proportion that is suitable to participate in a PoC trial (Chapter 3). To this end, we have created three applications for entry and visualisation of metrics concerning the Register (i.e., pre-LCS or 'pre-screening' information). Two of these pertain to batch-wise metrics on a summary level, exploring rates and reasons for attrition between request and enrolment. TDC staff have received training for these applications, allowing for their use by 9 sites. A third application enables the visualisation of information on a derID (individual) level, made possible by the Central Archive system of the 'PREPAD' software. This application lets users explore time courses and biases due to subject and PC characteristics.

Main dissemination activities of WP3 consisted of trainings at Investigators Meetings and an oral presentation about the EPAD Register at the Alzheimer's Association International Conference in London (Chapter 6). Looking ahead, we will work on reports from information gathered through the tracking systems described in Chapter 3. In the coming months and years a challenge and opportunity is formed by the increasing number of TDCs and PCs, leading to a raised workload for WP3 that needs to be managed. The experience of the small core team and previous investments in a structured workflow are expected to be crucial during the next phase of the project.

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