

Executive Summary

The EPAD Registry approach was set up as an innovative framework to find the participants for the EPAD studies from Parent Cohort (PCs) across Europe. Previous deliverables provide a complete description of the set-up of the Registry and its workflows (deliverable 3.3/3.4) and the final Registry status including the additional tools created during the project (deliverable 3.8). This final deliverable provides an overview report from the EPAD Registry from start to sustainability. We included the WP3 scientific output and lessons learned and future directions.

PCs all provided a 'fingerprint' of their cohort in the specifically adapted EMIF-EPAD catalogue. Collaboration contracts were set up and a data/subject discovery infrastructure was adapted to EPAD. The Registry approach successfully facilitated recruitment in the longitudinal cohort study from the start of the project. During the project, recruitment objectives evolved and new tools were developed, primarily by ULEIC researchers. WP3 published the Registry framework and the results in two top dementia journals: *Alzheimer's & Dementia* (Vermunt et al., 2018) and *In Alzheimer Research & Therapy* (Vermunt et al., 2020), presented at AAIC in 2016 poster (+Alzforum coverage), 2017 Oral presentation, at CTAD in 2018 with a poster (+Alzforum coverage), poster at IMI symposium 2019, and organized a workshop on recruitment science for sharing expertise across diverse register-type approaches (GA 2017 & 2019; February 2019 in Amsterdam).

Multiple nationwide registers have been initiated in the slipstream of EPAD, which will have long-reaching impact as independent projects, facilitating research participation and inspiring novel recruitment and research practice. WP3 has been consulted for example in the Netherlands for the Hersenonderzoek.nl, in the UK for Great Minds, in Scotland for the Scottish Brain Health Register, in Germany the Köln Registry and Bavaria Registry, in Italy for Italian version of Brain Health registry, in Finland/Sweden for setting up a register. Practices have also been shared by the Spanish and French EPAD sites, also leaders on registry-type approaches in Europe, which provided learnings for others. The Registry platform and related learnings in recruitment science, are important impacts of the EPAD program, all of which will endure beyond the funding period. Sustainability is also foreseen in terms of collaboration with GAP-net, which will focus on applying the developed tools to facilitate direct recruitment for clinical trials.

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