



Executive Summary

In this deliverable we describe the process of collecting meta-data of Parent Cohorts (PCs), the so called fingerprinting. Fingerprinting will provide a level of details sufficient to select PCs that can potentially provide research participants for the EPAD longitudinal cohort study (LCS). These PCs will be connected to the EPAD register.

We first have defined the steps of how to engage with potential PCs. This was done together with the national leads, the legal team and Project Management Organization (PMO). We use the tools developed as part of EMIF for fingerprinting and adjusted it for the needs of EPAD in a way that it streamlines and reduces the time needed for the fingerprinting process for PCs.

In the last section information on the progress of the fingerprinting of PCs per region is provided. It contains information on 11 fingerprinted cohorts which give potential access to 17585 research participants that could be invited to participate in the EPAD cohort and PoC of which 6519 are classified as research participants with normal cognition and 2975 as Subjective Cognitive Impairment (SCI) and 3019 as Mild Cognitive Impairment (MCI) research participants. All these cohorts are linked to project partners. For the other cohorts a timeline is given if possible.

Four documents are provided as appendix: I. An overview of the most important meta-data of the PCs that have been fingerprinted. II. Q&A to explain the EPAD register to interested collaborators. III. Manual on how to fill in the fingerprint in the EMIF-EPAD catalogue. IV. List of the variables of the fingerprint for EPAD.

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