A European Medical Information Framework for Alzheimer's disease (EMIF-AD)

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Background: There is an urgent need for validated and novel prognostic and diagnostic markers in preclinical and prodromal Alzheimer's disease (AD) and for a better understanding of the early pathophysiology of Alzheimer's disease (AD). In order to facilitate studies on predementia AD we setup of a European Medical Information Framework (EMIF, www.emif.eu) for AD that will enable optimal use of existing data cohorts. The objectives of the EMIF-AD platform are to provide a catalogue with information on study characteristics of cohort studies in Europe, to provide a database structure that can be used to pool data from different cohorts, and to provide a data storage and data sharing facility. Methods: We have approached cohort studies on aging or Alzheimer's disease to provide detailed information on their study design. A web-based browser was developed to store study characteristics and allow search queries that can identify cohorts that may provide information for specific research questions. In addition, using tranSMART a database taxonomy and data dictionary was set-up. Results: To date we have collected information on 23 cohort studies. These cohorts give access to data of 4000 subjects with normal cognition, 1500 with subjective complaints, 5000 with MCI and 3000 with AD. In these cohorts data have been collected on CSF markers (n=3000), MRI scans (n=8000), DNA (n=6000) and plasma or serum markers (n=5000). In tranSMART a selection of data from 3 cohorts have been pooled. Conclusions: The EMIF-AD platform will become a useful tool to facilitate data access, data pooling and collaborative studies on early AD. The platform is open for any cohort study to join. Funding EMIF-AD is funded by the EU/EFPIA Innovative Medicines Initiative (IMI) Joint Undertaking