

Publishable Summary

The AMYPAD PNHS data collection is a combination of prospective and historical data from 17 European sites in Belgium, France, Germany, Spain, Sweden, Switzerland, The Netherlands, and The United Kingdom. These sites have provided information through 11 parent cohorts, including EPAD LCS, EMIF-AD (60++ and 90+), ALFA+, FACEHBI, FPACK, UCL-2010-412, Microbiota, H70, DELCODE, and AMYPAD Diagnostic and Patient Management Study (DPMS).

The integration and harmonization of all these data sources resulted in the largest European dataset phenotyping longitudinally individuals at risk of AD-related progression. At the end of the project, the data set consists of ~9700 observations from 3350 subjects, ~1600 with baseline amyloid PET, and about 940 of them having at least one follow-up scan. All this information is organized into 614 variables, grouped into 68 concepts, and 13 domains (such as demographics, family history, genetics, vital signs, medical history, neuropsychological questionnaires, lifestyle, CSF, PET, and MRI).

To monitor the AMYPAD PNHS publication activities, a publication plan has been developed by the WP4 team in collaboration with the AMYPAD ExCom members. At the time of writing, 16 research proposals have been collected, aligned with the primary and secondary endpoints of the AMYPAD PNHS. Only one paper has been published, while all the other 15 are still ongoing and will be submitted after study termination.

After study termination, the AMYPAD PNHS data will be accessible to researchers via the Alzheimer's Disease Data Initiative (ADDI, <https://portal.addi.ad-datainitiative.org>) following the FAIR principles. Further details for the data access request can be found in "D1.7 Final Data & Knowledge Management Plan".

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Acknowledgement: This project has received funding from the Innovative Medicines Initiative 2 Joint Undertaking under grant agreement No 115952. This Joint Undertaking receives support from the European Union's Horizon 2020 research and innovation programme and EFPIA.



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