Publishable Summary

Following the deliverable D1.5 Interim Data Knowledge and Management Plan, this document aims to finalize the data and knowledge management policies of AMYPAD, especially referring to research data quality, sharing, and security, in coordination with several European collaborative studies.

The document focusses on the pseudo-anonymized clinical and neuroimaging data collected in the two studies that are running under AMYPAD, i.e., the Diagnostic and Patient Management Study (DPMS) and the Prognostic and Natural History Study (PNHS). In this document, the implemented strategy by AMYPAD regarding making the data FAIR (Findable, Attainable, Interoperable, andReproducible) can be found, including provisions for data storage, sharing, and long-term preservation, as well as for standard methodology and nomenclature conventions.

The plan established in this document might still be updated after the duration of the project's life as needed, in particular as the datasets and related project policies evolve, additional cohorts might join the AMYPAD collaborative framework, and to account for changes in legal requirements.

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