

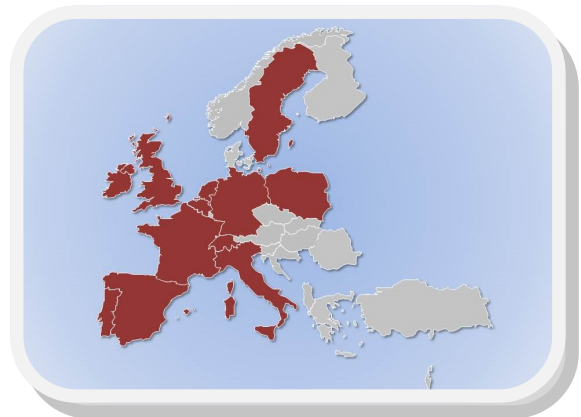
**NETCALs**

**A community-led Working Group for population-based cohorts of ALS patients**

Amyotrophic Lateral Sclerosis (ALS) is one of the most devastating lethal diseases in neurology. There is no cure for ALS. Research thus far suggests that ALS should no longer be considered a single disease and that different subgroups of patients exist. A major challenge in ALS research is to identify these different subgroups based on specific (combinations of) phenotypic, genetic, environmental or lifestyle characteristics or other biomarkers. Only transnational collaborations of ALS centres will be able to create a sample size with sufficient power to analyse the multiple layers of data to distinguish the subgroups.

The community-led Working Group 'NETCALs', consisting of key European ALS clinician scientists, focusses on establishing pan-European 'best practice' guidelines and a methodological framework for data sharing/handling, cognitive/functional outcome measures, standards for neuro-imaging/neurophysiology, and clinical data linkage in population-based cohorts of ALS patients and pre-symptomatic gene carriers, with the ultimate goals to increase sample size and to enable integration of multi-layer data sets. These deliverables will be of great value to overcome barriers to research in on-going and future patient cohort studies.






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