# SOPHIA: Sampling and biomarker optimisation and harmonisation in ALS and other motor neuro diseases

https://www.neurodegenerationresearch.eu/survey/sophia-sampling-and-biomarker-optimisation-and-harmonisation-in-als-and-other-motor-neuro-diseases/

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**Country**

Ireland

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SOPHIA: Sampling and biomarker optimisation and harmonisation in ALS and other motor neuro diseases

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4

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**Research Abstract**

Amyotrophic Lateral Sclerosis (ALS) is one of the most devastating diseases in neurology affecting some 50,000 individuals at any time in Europe, and causing around 10.000 deaths each year. The motor system (upper motor neurons in the motor cortex and lower motor neurons in the spinal cord) is preferentially affected, but there is an overlap with frontotemporal dementia (FTD). ALS represents a good model for study of all neurodegenerative conditions, as

it has a characteristic phenotype, rapid progression and the correlation between diagnosis during life and autopsy diagnosis is close to 100%. However, validated neurochemical biomarkers for monitoring disease activity, earlier diagnosis and defining prognosis are lacking. Active European collaborations are in place for harmonizing clinical datasets, neuroimaging and neuropathology protocols. A preliminary strategy for harmonization of biological and tissue samples has been established. Standardized protocols for clinical data and sample collection are now urgently required for optimization and harmonization of biomarker development. The overall aim of this proposal is to provide a common European strategy for the prioritization and selection of candidate biomarker domains for optimization and harmonization. This will in turn provide a long term platform by which existing collaborative structures that are relevant to neurodegenerative disease biomarkers (including academic initiatives, co-funding strategies, biobanks, industrial efforts, private-public alliances) are integrated within an inclusive web-based virtual biobank. Samples and clinical, imaging, neurophysiologic and neuropathological datasets provided by participating members can then be optimally utilized to enable state of the art collaborative analyses. The established platform will act as an important communication channel between this consortium and the broader international ALS/Neurodegeneration field, to ensure that the optimization efforts are consistently applied. This will avoid duplication of work, and will ensure that the outcome of the project will be accessible to, and utilized by all relevant stakeholders. Ultimately, the platform will establish a permanent Interactive European ALS biomarker tool for all researchers, and will enable ongoing optimization/harmonization of novel biomarkers using an integrated and robust pan-European ALS methodology. The platform will allow interaction with those of other cognate groups (e.g the NEALS group within the US), with patient groups and other relevant stakeholders.

**Further information available at:**

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Investments < €500k

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Ireland

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