

NEEDS in ALS

Network for determining existential decisions in Amyotrophic Lateral Sclerosis

The overall aim of the project is to determine factors of decisions to prolong or shorten life in patients with a severe life-threatening disease in different European countries. Amyotrophic lateral sclerosis (ALS) will serve as a model disease in which body functions are lost in a short period of time. Loss of movements and speech are most prominent and death usually occurs within 3-5 years. The reasons for decisions to prolong (with for example, mechanical ventilation) or shorten life (with for example, euthanasia) are mostly unknown.

ALS patients, caregivers and physicians will be interviewed in Germany, Sweden and Poland. Official records (legislative texts, health insurance standards and medical practice guidelines) will additionally be used. Individual factors (e.g. personal beliefs) will be distinguished from general factors (e.g. national healthcare policy). It will be a unique approach on how and why severely physically challenged patients decide the way they do and why decisions varies significantly between different European countries.

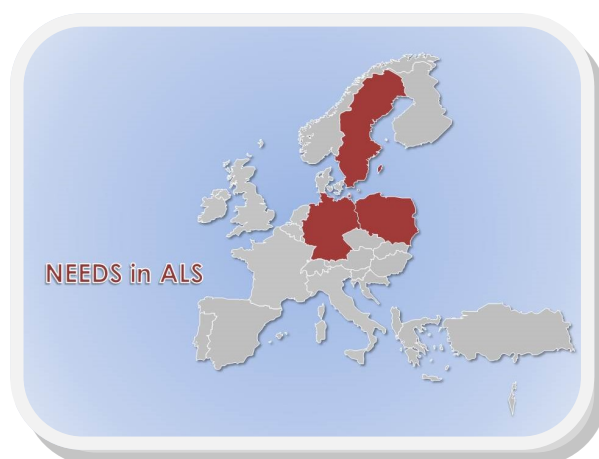
Data will impact on general discussions on living wills and end-of-life decision making policy. Best medical practice guidelines for clinicians and handbooks for patients will be provided. Workshops for expert and layman discussions will be organised.

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* Contributions from participating JPND Member Countries are currently being finalised for this project