

HEALTH-E-RND

European eHealth care model for rare neurodegenerative diseases

Rare neurodegenerative disorders (RND) like Huntington’s Disease (HD) require multidisciplinary care team which are in short supply. Given the devastating consequences of RNDs for the individual patient and their families there is an urgent need to develop innovative ways to deliver care.

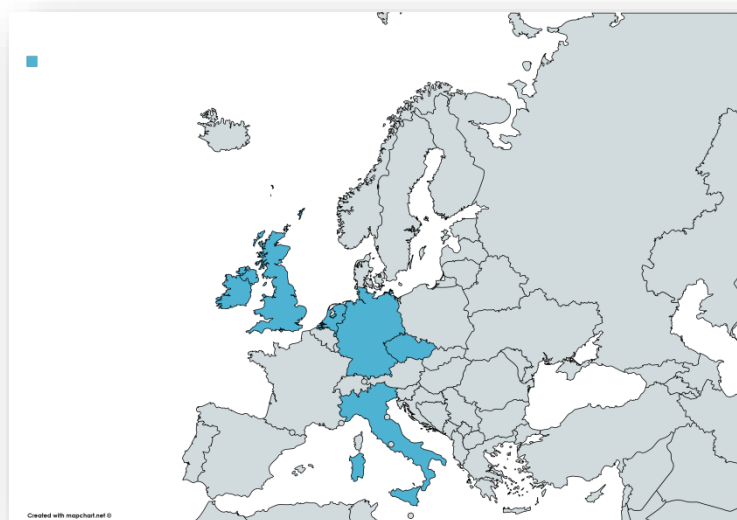
Our multi-national and -disciplinary consortium will harness the power of e-health care models and will engage in the co-development of need-based Quality of Life (QoL) assessments and an eHealth care model for rare neurodegenerative diseases by conducting a proof of concept study in HD. We will first develop disease-specific QoL measures for HD patients and HD care-givers using the needs-based conceptual model, implement and test for feasibility a multidisciplinary, multilingual multicultural e-health care model and then evaluate the effectiveness and the impact of the e-health care model by conducting a proof of concept randomized controlled trial using assessing needs-based quality of life measurements as primary outcome.

Overall, the project is expected to provide a model for the improvement and optimization of existing health care strategies for RND across Europe and may hasten the development of new health care approaches.

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