

**LERU STudent REseArch Mobility Programme (STREAM)
Project proposal**



Host University:
Università degli studi di Milano



Field:
Health

Specified field, subject:
Biomedical sciences, clinic trials

Research project title:
Italian validation of the myotonic dystrophy health index (MDHI)

Possible starting month(s):

Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug
x				x							



Possible duration in months:

1	2	3	4	5	6
					x



Suitable for students in: 2nd cycle (Master students)

Prerequisites: psychologists, physiotherapists, nurses

Restrictions: none

Description:

BACKGROUND: Myotonic Dystrophy type 1 is a heterogeneous disorder. The Myotonic Dystrophy Health Index (MDHI) is patient-reported measure of disability and impact of the disease on the patients lives (Heatwole et al., 2014). The way this instrument has been constructed is based on the idea that it highlights those symptoms which are most relevant and significant for patients with DM1. **AIMS:** The aim of this study is the translation and validation of the MDHI in Italian so that it can be applied in clinical and research settings in Italy. The application of the MDHI to the Italian population will allow to verify whether items considered to be frequent and important to the US population are the same in Italy. The availability of the MDHI questionnaire in Italian will give the possibility to use the same instrument in international clinical trials which are ongoing in the US and which are expected in Europe in the near future.

METHODS: The validation process will occur at the NEMO Center in Milan and will address 50 patients with DM1 at all stages of the disease process. The questionnaire is made up of 17 questions which explore several domains of the disease (mobility, difficulties in the hands and arms, limitations in everyday activities, fatigue, pain, gastrointestinal problems, eye problems, difficulties with speech and communication, sleep, emotional aspects, difficulties with attention and concentration, swallowing problems, hearing limitations. There are 114 questions in total and it takes 20 minutes roughly to be completed. The validation process will include: a) translation and back



translation of the questionnaire; b) administration of the MDHI to a sample of 8 patients; c) adaptation and changes to the wording and phrasing according to the patients' comments; d) administration of the final MDHI version to a sample of 50 patients with Myotonic Dystrophy type 1; e) content validity; f) reliability by test-retest.

EXPECTED RESULTS: We expect to provide the Myotonic Dystrophy community including patients, families and health operators with a measure of symptoms and impact in this disorder that will potentially be an outcome measure in the near future international clinical trials in this disorder. Psychologists, nurses or physiotherapists will be able to improve their approach to diseases having multiple organ involvement and which are associated with several degrees of disability and impairment. The validation process will provide the methodological basis to any validation process which requires cross-cultural and qualitative and quantitative analysis.

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