DEVELOPING A MULTIPLE SYSTEM ATROPHY PAIN SCALE

DG/WG
Atypical Parkinsonism

Alessandra Fanciulli, Nicole Campese, Klaus Seppi, Werner Poewe, Georg Goebel, Günther Höglinger, Johannes Levine, Giovanna Calandra Buonaura, Pietro Guaraldi, Roberto Eleopra, Maria Grazia Devigili, Wassilios Meissner, Dr David Bendetowicz, Margherita Fabbri, Anne Pavy-Le Traon, Christine Brefel-Courbon, Anette Schrag, Ray K. Chaudhuri, Michele Tinazzi, Maria Teresa Pellecchia, Günther Deuschl, Elizabeth Coon, Horacio Kaufmann, Roy Freemann, Jeanne Curtis

Medical University of Innsbruck, AT; Ludwig Maximilians University Hospitals, Munich, DE; IRCCS Institute of Neurological Sciences of Bologna, IT; IRCCS Carlo Besta Neurological Institute, Milan, IT; CHU Bordeaux, FR; CHU Toulouse, FR; University College London, UK; King´s College London, UK; University of Verona, IT; University of Salerno, IT ; University of Kiel, DE; Mayo Clinic, USA; New York University, USA ; Harvard Medical School, USA.

Introduction

Multiple system atrophy (MSA) is a rare, rapidly progressive neurodegenerative disorder of adulthood, characterized by autonomic and motor dysfunction in various combinations. Besides that, a constellation of non-motor symptoms may affect persons living with MSA, including pain. According to a recent survey, pain affects up to 86% of persons living with MSA, impacting the quality of life and activities of daily living[1,2].
Except for the MSA quality of life questionnaire[3], no validated patient-reported outcome measures (PROMs) exist to assess the impact of core MSA features on daily life and no MSA-specific pain assessment tools are now available.

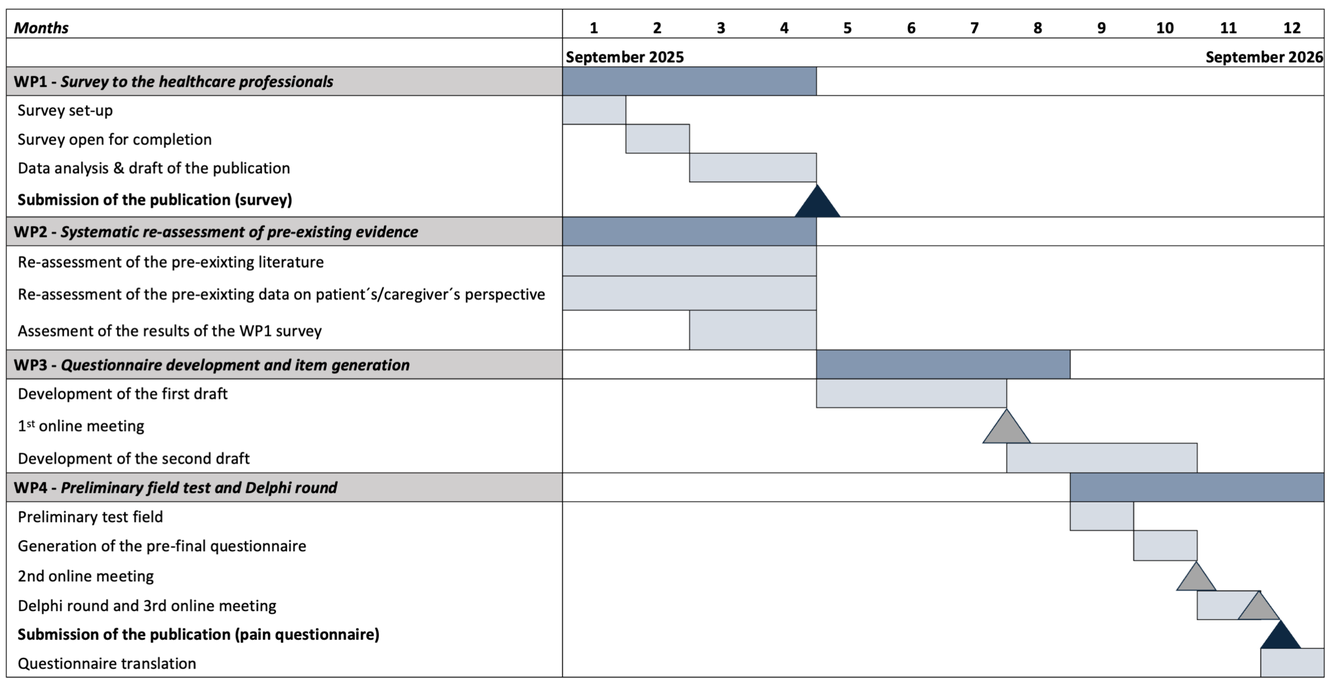
Created with posts from the MSA Coalition Facebook® public discussion group

Goal

The goal of this project is to develop and validate a self-reported pain assessment tool specifically designed for persons with MSA.

Work Plan

The project is expected to start in September 2025 and will be articulated into four work-packages (see figure below):
Work package 1 (WP1) – *Health care professionals survey on pain-related unmet clinical needs in MSA (month 1-4).*
Work package 2 (WP2) - *Systematic re-assessment of the pre-existing evidence (month 1-4).*
Work package 3 (WP3) – *Questionnaire development and item generation (month 5-8)*
Work package 4 (WP4) – *Preliminary field test and Delphi round (month 9-12)*



Outlook

The development and validation of a MSA-tailored pain questionnaire will:
- Promote and standardise pain assessment in modern MSA clinical practice.
- Pave the way for a better understanding of the pathophysiological basis of pain in MSA.
- Guide the development of pain treatment strategies based on its causes and characteristics
- Provide validated outcome measures for future clinical trials to treat pain in MSA.

European Reference Network
for rare or low prevalence complex diseases
Network Neurological Diseases (ERN-RND)

References: [1]Campese et al., Mov Disord 2024; [2]Campese et al., Mov Disord Clin Pract 2023; [3]Schrag et al., Mov Disord 2007

Funded by the European Union