

OPTIMIZED CLINICAL ATAXIA SCALE - SARA PATIENT PERSPECTIVE



DG
Ataxia & HSP

Introduction

This ERN-RND–funded project addresses the need for a reliable and patient-centered clinical outcome assessment for ataxia. The Scale for the Assessment and Rating of Ataxia (SARA) is the most widely used clinician reported outcome measure (ClinRO) but has been criticized for limited anchoring in patient experience, questionable interpretability of some items, and variable sensitivity to change. Our objective is to optimize SARA by integrating patient-reported symptoms, harmonizing scoring ranges, and validating the optimized version, while ensuring compatibility with existing SARA datasets.

Results

The first major milestone has been achieved with the collection of large-scale patient experience data comprising data from >800 patients (Table). A first joint online consensus meeting was successfully held in August 2025 with clinical experts and representatives from patient advocacy groups and industry. The consensus meeting set the stage for a structured review of the SARA, and an expert committee is currently compiling ambiguities in the wording and application of SARA items, which will inform subsequent modifications. A work group on patient perspective is currently engaged in symptom clustering and merging of the available datasets.

Variable	Lowit et al.	Biohaven - SCA Disease Burden	SPATAX	Gorocenco et al.
Participants	366	80	293	75
Age	yes	yes	yes	yes
Gender	yes	yes	yes	yes
Diagnosis	no	yes (SCA1, 2, 3, 6)	yes (cerebellar ataxias)	no (genetic yes/no)
Disability Stage	no	mod Klockgether stages	FARS Disability Stages	SARA + disability based on walking
Symptoms	tickboxes + free text	free text (3 most important symptoms)	Tickboxes	current symptoms (free text)
Severity Ranking	top 3 mentioned symptoms	ranking (0-100 points)	no/ small/ moderate/ severe/ very severe effect	most difficult in daily life/ restrictions (?)

Table: Summary of variables in available datasets

Outlook

The next steps include finalizing the mapping of patient-reported symptoms to define the concept of interest and its representation within the current SARA. Based on these insights, the 2nd consensus roundtable will be prepared to determine the required modifications. An optimized version of SARA and its instructions will then be developed and subsequently validated.