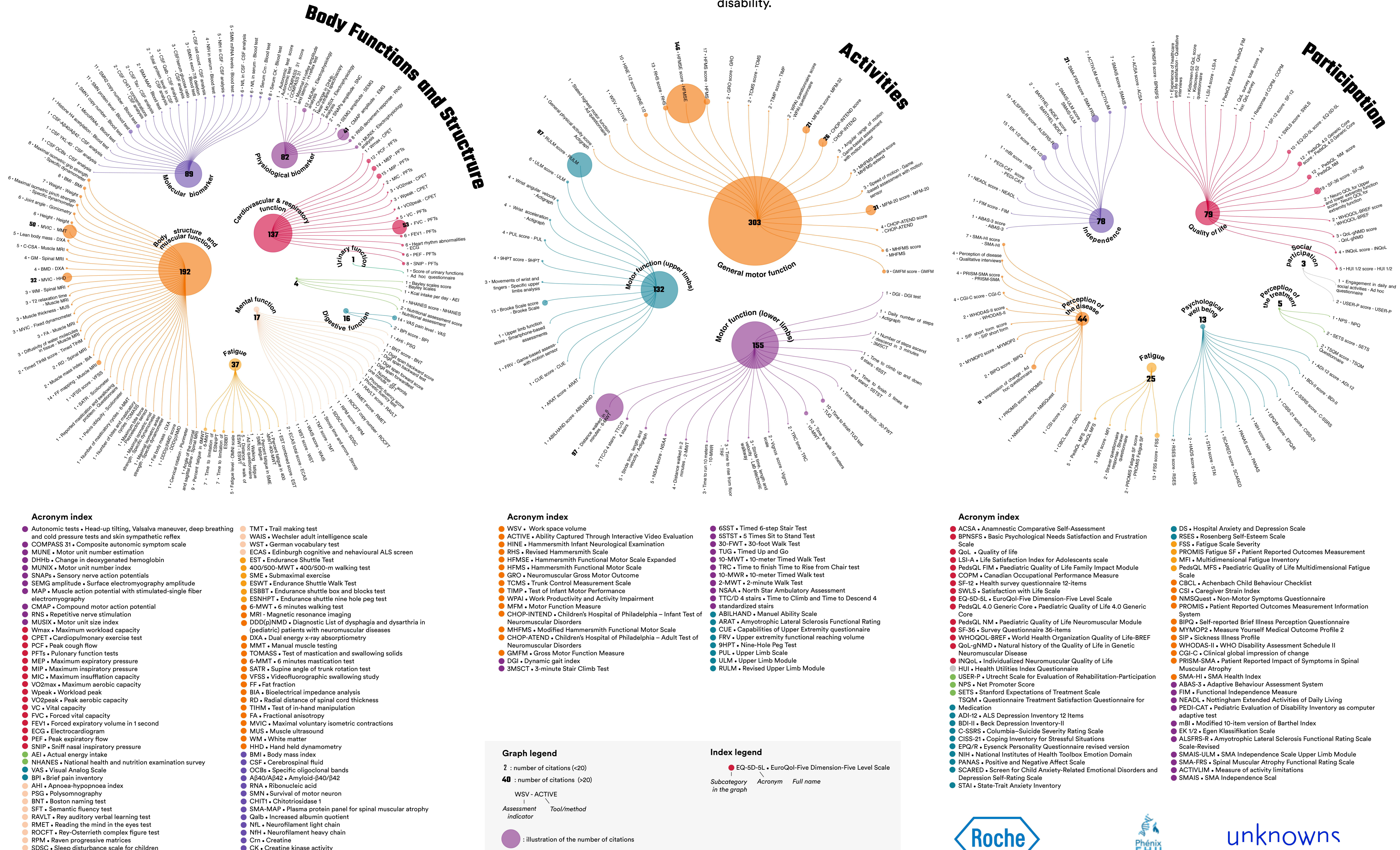


# A MAPPING OF ASSESSMENT INDICATORS FOR SMA ADOLESCENT AND ADULT PATIENTS

Data presented in this poster come from a scoping review on the assessment indicators and their associated measurement tool/methods used for SMA adolescent and adult patients. This review analyzes 410 scientific articles regarding the assessment of SMA adolescent and adult patients, published between January 2012 and June 2022 and identified from 3 databases (PubMed, Embase and Cochrane). The categorisation of the assessment indicators identified is based on International Classification of Functioning, Disability and Health (ICF), which is a standard framework for the definition and measurement of functioning and disability.



- ### Acronym index
- Autonomic tests • Head-up tilting, Valsalva maneuver, deep breathing and cold pressure tests and skin sympathetic reflex
  - COMPASS 31 • Composite autonomic symptom scale
  - MUNE • Motor unit number estimation
  - DHbH • Change in deoxygenated hemoglobin
  - MUNIX • Motor unit number index
  - SNAPs • Sensory nerve action potentials
  - SEMG amplitude • Surface electromyography amplitude
  - MAP • Muscle action potential with stimulated-single fiber electromyography
  - CMAP • Compound motor action potential
  - RNS • Repetitive nerve stimulation
  - MUSIX • Motor unit size index
  - Wmax • Maximum workload capacity
  - CPET • Cardiopulmonary exercise test
  - PCF • Peak cough flow
  - PFTs • Pulmonary function tests
  - MEP • Maximum expiratory pressure
  - MIP • Maximum inspiratory pressure
  - MIC • Maximum insufflation capacity
  - VO2max • Maximum aerobic capacity
  - Wpeak • Workload peak
  - VO2peak • Peak aerobic capacity
  - VC • Vital capacity
  - FVC • Forced vital capacity
  - FEV1 • Forced expiratory volume in 1 second
  - ECG • Electrocardiogram
  - PEF • Peak expiratory flow
  - SNIP • Sniff nasal inspiratory pressure
  - AEI • Actual energy intake
  - NHANES • National health and nutrition examination survey
  - VAS • Visual Analog Scale
  - BPI • Brief pain inventory
  - AHI • Apnoea-hypopnoea index
  - PSG • Polysomnography
  - BNT • Boston naming test
  - SFT • Semantic fluency test
  - RAVLT • Rey auditory verbal learning test
  - RMET • Reading the mind in the eyes test
  - ROCF • Rey-Osterrieth complex figure test
  - RPM • Raven progressive matrices
  - SDSC • Sleep disturbance scale for children
  - TMT • Trail making test
  - WAIS • Wechsler adult intelligence scale
  - WST • German vocabulary test
  - ECAS • Edinburgh cognitive and behavioural ALS screen
  - EST • Endurance Shuttle Test
  - 400/500-MWT • 400/500-m walking test
  - SME • Submaximal exercise
  - ESWT • Endurance Shuttle Walk Test
  - ESBBT • Endurance shuttle box and blocks test
  - ESNHPT • Endurance shuttle nine hole peg test
  - 6-MWT • 6 minutes walking test
  - MRI • Magnetic resonance imaging
  - DDD(g)NMD • Diagnostic List of dysphagia and dysarthria in (pediatric) patients with neuromuscular diseases
  - DXA • Dual energy x-ray absorptiometry
  - MMT • Manual muscle testing
  - TOMASS • Test of mastication and swallowing solids
  - 6-MMT • 6 minutes mastication test
  - SATR • Supine angle of trunk rotation test
  - VFSS • Videofluorographic swallowing study
  - FF • Fat fraction
  - BIA • Bioelectrical impedance analysis
  - RD • Radial distance of spinal cord thickness
  - TIHM • Test of in-hand manipulation
  - FA • Fractional anisotropy
  - MVIC • Maximal voluntary isometric contractions
  - MUS • Muscle ultrasound
  - WM • White matter
  - HHD • Hand held dynamometry
  - BMI • Body mass index
  - CSF • Cerebrospinal fluid
  - OCBs • Specific oligoclonal bands
  - Aβ40/Aβ42 • Amyloid-β40/β42
  - RNA • Ribonucleic acid
  - SMN • Survival of motor neuron
  - CHIT1 • Chitotriosidase 1
  - SMA-MAP • Plasma protein panel for spinal muscular atrophy
  - Qalb • Increased albumin quotient
  - NFL • Neurofilament light chain
  - NfH • Neurofilament heavy chain
  - Crn • Creatine
  - CK • Creatine kinase activity

- ### Acronym index
- WV • Work space volume
  - ACTIVE • Ability Captured Through Interactive Video Evaluation
  - HINE • Hammersmith Infant Neurological Examination
  - RHS • Revised Hammersmith Scale
  - HFMS • Hammersmith Functional Motor Scale Expanded
  - GRS • Hammersmith Functional Motor Scale
  - GRO • Neuromuscular Gross Motor Outcome
  - TOMS • Trunk Control Measurement Scale
  - TIMP • Test of Infant Motor Performance
  - WPA • Work Productivity and Activity Impairment
  - MFMM • Motor Function Measure
  - CHOP-INTEND • Children's Hospital of Philadelphia – Infant Test of Neuromuscular Disorders
  - MHfMS • Modified Hammersmith Functional Motor Scale
  - FRV • Upper extremity functional reaching volume
  - 9HPT • Nine-Hole Peg Test
  - PUL • Upper Limb Scale
  - ULM • Upper Limb Module
  - RULM • Revised Upper Limb Module
  - 6SST • Timed 6-step Stair Test
  - 5STST • 5 Times Sit to Stand Test
  - 30-FWT • 30-foot Walk Test
  - TUG • Timed Up and Go
  - 10-MWT • 10-meter Timed Walk Test
  - TRC • Time to finish Time to Rise from Chair test
  - 10-MWR • 10-meter Timed Walk test
  - 2-MWT • 2-minute Walk Test
  - NSAA • North Star Ambulatory Assessment
  - EQ-5D-5L • EuroQol-Five Dimension-Five Level Scale
  - standardized stairs
  - ABILHAND • Manual Ability Scale
  - ARAT • Amyotrophic Lateral Sclerosis Functional Rating
  - CUE • Capabilities of Upper Extremity questionnaire
  - FRV • Upper extremity functional reaching volume
  - 9HPT • Nine-Hole Peg Test
  - PUL • Upper Limb Scale
  - ULM • Upper Limb Module
  - RULM • Revised Upper Limb Module
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  - PUL • Upper Limb Scale
  - ULM • Upper Limb Module
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- ### Acronym index
- ACSA • Anamnestic Comparative Self-Assessment
  - BPNSFS • Basic Psychological Needs Satisfaction and Frustration Scale
  - QoL • Quality of life
  - LSI-A • Life Satisfaction Index for Adolescents scale
  - PedsQL FIM • Paediatric Quality of Life Family Impact Module
  - PedsQL MFS • Paediatric Quality of Life Multidimensional Fatigue Scale
  - PedsQL MFS • Paediatric Quality of Life Multidimensional Fatigue Scale
  - CBCL • Achenbach Child Behaviour Checklist
  - CSI • Caregiver Strain Index
  - NMSQuest • Non-Motor Symptoms Questionnaire
  - PROMIS • Patient Reported Outcomes Measurement Information System
  - PedsQL NM • Paediatric Quality of Life Neuromuscular Module
  - SF-36 • Survey Questionnaire 36-items
  - WHOOQOL-BREF • World Health Organization Quality of Life-BREF
  - QoL-NMD • Natural history of the Quality of Life in Genetic Neuromuscular Disease
  - INQoL • Individualized Neuromuscular Quality of Life
  - HUI • Health Utilities Index Questionnaire
  - USER-P • Utrecht Scale for Evaluation of Rehabilitation-Participation
  - NPS • Net Promoter Score
  - SETS • Stanford Expectations of Treatment Scale
  - TSQM • Questionnaire Treatment Satisfaction Questionnaire for Medication
  - ADI-12 • ALS Depression Inventory 12 Items
  - BDI-II • Beck Depression Inventory-II
  - C-SRRS • Columbia-Suicide Severity Rating Scale
  - CISS-21 • Coping Inventory for Stressful Situations
  - EPQ/R • Eysenck Personality Questionnaire revised version
  - NIH • National Institutes of Health Toolbox Emotion Domain
  - PANAS • Positive and Negative Affect Scale
  - SCARED • Screen for Child Anxiety-Related Emotional Disorders and Depression Self-Rating Scale
  - STAI • State-Trait Anxiety Inventory
  - DS • Hospital Anxiety and Depression Scale
  - RSES • Rosenberg Self-Esteem Scale
  - FSS • Fatigue Scale Severity
  - PROMIS Fatigue SF • Patient Reported Outcomes Measurement
  - MFI • Multidimensional Fatigue Inventory
  - PedsQL MFS • Paediatric Quality of Life Multidimensional Fatigue Scale
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  - STAI • State-Trait Anxiety Inventory

- ### Graph legend
- 2 : number of citations (<20)
  - 40 : number of citations (>20)
  - WSV - ACTIVE
  - Assessment
  - Tool/method
  - indicator
  - : illustration of the number of citations
- ### Index legend
- EQ-5D-5L • EuroQol-Five Dimension-Five Level Scale
  - Subcategory in the graph
  - Acronym
  - Full name

