

Rasch-built Overall ALS Disability Scale (ROADS) – Training Manual

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BACKGROUND (1)

- The Rasch-built Overall ALS Disability Scale (ROADS) is a patient-reported outcome measure that assesses overall disability level in people with ALS.
- The scale contains 28 items, each scored 0, 1, or 2.
- The scale was constructed and validated using Rasch analyses - a modern test-theory technique that produces linearly-weighted scales, meaning that a 1-point change is a quantifiable, consistent measurement of disability across the scale, and a 2-point change reflects twice the amount of disability.

ROADS PROPERTIES (1-4)

- Test-retest reliability for the ROADS is 97%.
- In an ALS clinic population where ALSFRS-R declined by a mean of 0.76 (SD = 1.09) points per month, ROADS normed score declined by a mean of 2 points per month (SD = 2.44).
- When evaluating patient-defined clinically meaningful change, patients rated average ROADS changes of 5.8 normed points and average changes of 3.2 ALSFRS-R points as clinically meaningful.
- ROADS electronic completion takes on average 3.8 minutes to complete.
- ROADS scores correlate with survival.
- The ROADS is currently validated in English (US), Italian, and Chinese.

ROADS INSTRUCTIONS

- The person with ALS should provide the answers for all questions.
 - A caregiver or staff member can enter the answers on paper or in the computer or serve as a scribe.
 - For clinical use, telephone administration and caregiver completion has also been validated, but patient-reported responses are recommended for highest reliability in the setting of a clinical trial.

- Staff should NOT provide coaching for individual answer responses – this ensures the same rater each time (the patient).
 - The clinician or staff member can direct the patient back to the main instructions if questions arise.
- ROADS items are not all region-specific (ex. some tasks involve upper extremities and bulbar function) – the abnormal option should be selected if the task is different or abnormal or slower or less efficient or modified for any reason.
- Participant Instructions:

“INSTRUCTIONS: This is a questionnaire about the relationship between your daily activities and your health. Your answers give information about how your ALS affects your daily and social activities and to what degree you are able to perform your usual activities.

Answer each question by marking the correct box (“X”). If you are not sure about your ability to perform a task, you are still requested to mark an answer that comes as close as possible to your judged ability to complete such a task. All questions should be completed. You can only choose one answer for each question. If your situation fluctuates, your answer should be based on how you usually perform the task.”

- The normed score (0-146) should be used for all data analyses. The normed score can be determined from the raw total score by using the conversion table on the final page of the ROADS document.

ROADS SCORING

[2] Normal: able to perform without difficulty.

- The task is performed as easily and as quickly as before onset of ALS symptoms.
- The task is performed no differently now than before ALS symptom onset.

[1] Abnormal: able to perform, but with difficulty

- The task can still be performed, but it is harder to perform now or takes more time or effort compared to before ALS symptom onset.
- The task is performed with the assistance of a device or with the assistance of another person.

[0] Unable to perform.

- The patient cannot perform the task

References

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3. Manera U, Solero L, Fournier CN, Canosa A, Vasta R, Bombaci A, et al. Validation of the Italian version of the Rasch-Built Overall Amyotrophic Lateral Sclerosis Disability Scale (ROADS) administered to patients and their caregivers. *Amyotroph Lateral Scler Frontotemporal Degener.* 2021:1-6.
4. Sun C, Fournier CN, Ye S, Zhang N, Ma Y, Fan D. Chinese validation of the Rasch-Built Overall Amyotrophic Lateral Sclerosis Disability Scale. *Eur J Neurol.* 2021;28(6):1876-83.