

Predicting clinician-recorded EDSS severity from patient-reported outcomes: evidence from the UK MS Register

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Background: Expanded Disability Status Scale (EDSS) is the standard multiple sclerosis (MS) disability assessment, routine clinical EDSS (cEDSS) assessment can have less availability than patient-reported outcomes (PROs).

Aim: To evaluate whether linked webEDSS, MSIS-29, HADS, MSWS-12, EQ-5D, and demographic and MS-specific (DMSS) variables can predict cEDSS, and to compare the performance of webEDSS alone with multivariable models.

Methods: A dataset containing one observation per participant with cEDSS was matched to PRO data collected at the same time. cEDSS was grouped into Mild (0-3.5), Moderate (4.0-5.5), and Severe (6.0-10.0). Three CatBoost multiclass models were developed for comparison: (1) PRO+DMSS without webEDSS, (2) PRO+DMSS with grouped webEDSS, and (3) PRO+DMSS plus non-grouped webEDSS. Assessment used repeated stratified splits and were evaluated using classification evaluation metrics. WebEDSS alone as a predictor of cEDSS severity was also evaluated.

Results: All models performed well for predicting EDSS severity. The best-performing model used webEDSS (non-grouped) alongside the questionnaire and DMSS variables, mean accuracy 0.817, balanced accuracy 0.807 and weighted kappa 0.818. The model excluding webEDSS performed slightly less well (accuracy 0.802; weighted kappa 0.807), suggesting that PROs and DMSS variables contain substantial disability-related information. WebEDSS alone showed moderate agreement with cEDSS severity (accuracy 0.737; kappa 0.582), with stronger discrimination for Mild and Severe categories than for Moderate EDSS. Across models, discrimination was strongest for Mild and Severe EDSS and weaker for Moderate EDSS. WebEDSS, walking-related MSWS-12 items, time since onset, and MS type were among the strongest predictors.

Conclusion: Linked PROs can predict EDSS severity with good discrimination and outperform WebEDSS alone, but combining webEDSS with PROMs and clinical-history variables provides the best performance. PROs and DMSS variables alone also perform well, supporting their usefulness as proxies for disability severity where clinician-recorded EDSS is unavailable.