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Validation of a Parkinson's disease questionnaire-39-based functional mobility composite score (FMCS) in people with Parkinson's disease

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ABSTRACT

Introduction: Functional mobility is an important outcome for people with Parkinson's disease (PwP). Despite this, there is no established patient-reported outcome measure that serves as a gold standard for assessing patient-reported functional mobility in PwP. We aimed to validate the algorithm calculating the Parkinson's Disease Questionnaire-39 (PDQ-39) based Functional Mobility Composite Score (FMCS).

Methods: We designed a count-based algorithm to measure patient-reported functional mobility in PwP from items of the PDQ-39 subscales mobility and activities of daily living. Convergent validity of the algorithm calculating the PDQ-39-based FMCS was assessed using the objective Timed Up and Go ($n = 253$) and discriminative validity was assessed by comparing the FMCS with patient-reported (MDS-UPDRS II) and clinician-assessed (MDS-UPDRS III) motor symptoms as well as between disease stages (H&Y) and PIGD phenotypes ($n = 736$). Participants were between 22 and 92 years old, with a disease duration from 0 to 32 years and 64.9% in a H&Y 1–2 ranging from 1 to 5.

Results: Spearman correlation coefficients (r_s) ranging from −0.45 to −0.77 ($p < 0.001$) indicated convergent validity. Hence, a *t*-test suggested sufficient ability of the FMCS to discriminate ($p < 0.001$) between patient-reported and clinician-assessed motor symptoms. More specifically, FMCS was more strongly associated with patient-reported MDS-UPDRS II ($r_s = -0.77$) than clinician-reported MDS-UPDRS III ($r_s = -0.45$) and can discriminate between disease stages as between PIGD phenotypes ($p < 0.001$).

Conclusion: The FMCS is a valid composite score to assess functional mobility through patient reports in PwP for studying functional mobility in studies using the PDQ-39.

Abbreviations: PwP, People with Parkinson's disease; FMCS, Functional Mobility Composite Score; ADL, Activities of Daily Living; FM, Functional Mobility; PDQ-39, Parkinson's disease Questionnaire 39; PROM, Patient-Reported Outcome Measure; PDD, Parkinson's disease dementia; TUG, Timed Up and Go; BDI-I, Beck Depression Inventory I; PIGD, Postural Instabilities and Gait Difficulty; SOP, Standardized Operation Procedures; H&Y, Hoehn & Yahr.

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1. Introduction

Parkinson's disease (PD) is a complex neurodegenerative disorder resulting in a wide variety of motor and non-motor symptoms. The development of postural instability is considered an important hallmark of clinical progression in PD [1]. Tosserams, de Vries, Bloem and Nonnekes [2] illustrated detrimental consequences for the participation of affected individuals in activities of daily living (ADLs). These consequences are due to impairments in functional mobility (FM), i.e. to move independently and safely in a variety of environments in order to accomplish functional activities or tasks and to participate in ADLs at home, work and in the community [3]. This so-called "functional mobility" of people with PD (PwP) worsens as the disease progresses [4,5] and impacts daily life. In particular, impaired functional mobility is associated with a loss of independence [6], activity limitation [7,8], falls [9], decreased social participation [10], increased self-stigma [11], and lower quality of life [12]. According to a recent update of the top 10 research priorities for the management of Parkinson's disease [13], improvement of function and reduction of balance problems remain important research priorities for PwD, their significant others and health professionals.

No established instrument specifically assesses functional mobility through patient reports [14] although a patient-reported instrument would be feasible in different settings (clinic, home care, research), and would be less costly and invasive compared to objective physical performance tests. Notably, Patient-Reported Outcome Measures (PROMs) provide patients' perspectives and are often the outcomes of most importance to patients [15]. The "Mobility" and the "Activities of Daily Living" subscales of the PDQ-39 Health-related Quality of Life Questionnaire [16] have been applied individually to measure functional mobility through patient reports in previous research [17–20] but neither were originally developed nor validated to assess functional mobility. Their use for this purpose however implies a need for such scales and indicates that these established subscales may be worth investigating in terms of their validity for assessing functional mobility, until a new instrument could be developed, validated and translated. To this end, we combined these two subscales in an algorithm calculating the PDQ-39-based functional mobility composite score (FMCS) to measure patient-reported functional mobility. A further advantage of the algorithm calculating the PDQ-39-based FMCS is that there is no need for PwP to complete an additional questionnaire, reducing their burden. As detailed in the supplement section 1.1, content validity, structural validity, test-retest-reliability, internal consistency and construct validity have previously been confirmed separately for the individual subscales included in our composite score. However, the convergent validity with an instrument assessing functional mobility has never been studied.

In this study, we aimed to validate the algorithm calculating the PDQ-39-based FMCS. As no gold standard for a PROM of functional mobility exists, we assessed the construct validity of the composite score. Consequently, we did not focus on the correlation with one gold standard but with several similar concepts.

2. Methods

2.1. Study design, setting and participants

The COSMIN guidelines [21] were used as methodological guideline for this study. This retrospective analysis is part of the Luxembourg Parkinson's study, a nation-wide, monocentric, observational, longitudinal-prospective study [22]. Among the participants are people with typical PD and Parkinson's disease dementia (PDD), living mostly at home in Luxembourg and the Greater Region (geographically close areas of the surrounding countries Belgium, France, and Germany). While the first patient was recruited in 2015, the systematic assessment of the Timed Up and Go (TUG) was added in November 2020.

As further described in supplement 1.1., after summing up the sixteen items of the PDQ-39 subscales mobility and activities of daily living [16], we transformed the FMCS score to a 0–100 scale according to the "User Manual" of the "The Parkinson's Disease Questionnaire" and inverted it by subtracting the individual score from the maximum score to enhance the interpretation of the results, i.e., a high score corresponds to good functional mobility.

$$\textit{FMCS Score} = 100 - \left(\frac{\textit{Sum of 16 items}}{(\textit{4 levels} * \textit{16 items})} * 100\right)$$

We formulated hypotheses about the relationships between the algorithm calculating the PDQ-39-based FMCS and other instruments measuring similar constructs. Additionally, hypotheses about differences in the FMCS between subgroups of patients were defined. Specifically, we evaluated the convergent validity by analyzing the association between the FMCS and similar constructs like the TUG [23], MDS-UPDRS-based Postural Instability and Gait Difficulty Score [24] and patient-reported and clinician-assessed motor symptoms (MDS-UPDRS II and III) [25]. We also compared the association between the FMCS and the MDS-UPDRS II and MDS-UPDRS III [25]. Additionally, we compared the association of the patient-reported symptoms of depression (BDI-I) with an objective measure of functional mobility (TUG) to the patient-reported FMCS to assess discriminant validity, as the FMCS should better reflect the emotional state of PwP than an instrument with objective measures. Finally, we compared the FMCS between the subgroups to assess for discriminant validity since the FMCS should be able to differentiate between people with early and moderate-advanced disease stages as well as between people with and without a Postural Instabilities and Gait Difficulty (PIGD)-dominant phenotype [24]. Detailed hypotheses can be found in the supplement. For the hypothesis-testing requiring TUG data, we included all 253 participants with typical PD or PDD (PwP) who performed a TUG in the Luxembourg Parkinson's study from November 2020 to December 2021. For the other analyses, we included all 736 PwP with a baseline assessment in the Luxembourg Parkinson's study. Participants with atypical PD were excluded from the analyses. Family members helped to complete the questionnaires if participants were having difficulties due to physical or cognitive impairments.

2.2. Variables and data collection procedure

2.2.1. PROM administration and comparison instruments

Participants of the Luxembourg Parkinson's study completed the PDQ-39 on paper at home prior to their baseline assessment while the TUG, MDS-UPDRS, BDI, and Hoehn and Yahr staging were completed during the baseline assessment onsite at the Parkinson's Research Clinic. We enabled standardized data collection by applying standardized operation procedures (SOP). Additionally, study nurses completed missing items in the patient-reported questionnaires during the baseline assessment together with the participants. Supplement Table S1 details the measurement instruments with which the FMCS is compared while Supplement Table S2 lists all other variables.

2.2.2. Quantitative variables

The variables analyzed in the convergent validation (i.e. MDS-UPDRS-based PIGD score, MDS-UPDRS II and III, TUG and BDI-I scores), were treated as numerical variables to retain all information. The grouping for the discriminative validation was organized as follows: early disease stages (H&Y stages 1, 1.5 and 2) and moderate-advanced disease stages (H&Y stages of 2.5–5). This grouping was chosen as H&Y stage 2.5 is marked by the appearance of postural impairment [1]. Participants with an MDS-UPDRS TD/PIGD ratio of $\leq$0.90 were classified as a PIGD-dominant phenotype while ratios of $>$0.90, i.e., tremor-dominant and intermediate phenotypes were classified as non-PIGD dominant phenotypes [24].

2.3. Statistical methods

Data analysis was carried out in R, version 3.6.3 [26]. We identified skewed data distribution by visual inspection of histograms and Q-Q-Plots (using the "ggplot2" package by Wickham [27]) combined with a significant Shapiro Test (using the "stats" package by R Core Team [26]) rejecting normality of the FMCS. However, we identified no departures from linearity in scatter plots (Fig. 1). Convergent validity was assessed by two-tailed Spearman correlation test (r_s). In addition, two t-tests tested for differences between correlation of FMCS with patient-reported and objective measures (using the "lavaan" package by Rosseel [28]). The two-sided Wilcoxon rank-sum tests (WRS) tested group differences to assess discriminative validity (using the "stats" package by R Core Team [26]). The hypotheses in the supplement provide more details. We defined a Bonferroni-adjusted 5% significance level of 0.05/8 to counteract the problem of multiple testing. We performed sensitivity power analyses in jamovi 2.2.5.0 [29] to calculate the minimum hypothetical effect size for which the chosen design will have the specified sensitivity. During the analysis, we handled missing data as a complete-case analysis.

3. Results

3.1. Participants characteristics

While 690 of 736 (93.8%) eligible participants with PD or PDD completed the items included in the composite score at home, we experienced challenges performing the TUG onsite during the COVID-19 pandemic, with many PwP preferring a telephone questionnaire. Consequently, data related to the TUG was missing in 60% (363/610) of all PwP recruited since the start of the systematic assessment of the TUG (which started in November 2020). Characteristics of study participants and the number of participants with missing data for each variable of interest are summarized in Table 1 and Supplemental Table S3. To enhance interpretation and give a clinical connotation to the scores, scores of the FMCS by various subgroups can be found in the supplement.

3.2. Convergent validity

As indicated in Fig. 1, the analyses of convergent validity to address the hypotheses 1–4 showed the FMCS correlates as expected with similar constructs, i.e. patient-reported and clinician-assessed postural instabilities and gait difficulties (A), observed functional mobility (B), patient-reported motor symptoms in daily living (C), and clinician-assessed motor symptoms (D). According to our sensitivity power analyses, our Spearman correlation tests with sample sizes of 253 and 736 will detect effect sizes of 0.16 and 0.09, respectively, with a probability greater than 0.8, assuming a two-sided criterion for detection that allows for a maximum Type I error rate of $\alpha = 0.05$.

3.3. Discriminative validity

Supplementary Tables S4 and S5 describe characteristics of the subgroups. As indicated in Fig. 2, Wilcoxon rank-sum tests to address the hypotheses 5 and 6 confirm statistically significant mean ranks differences, i.e. lower FMCS in participants in an moderate-advanced disease stage compared to those in early disease stages (A) corresponding to a higher difference than the mean change in score (3.65) that is subjectively meaningful to PwP according to the clinical significance threshold described in the supplement 1.1. An illustration of FMCS per disease stage can be found in the Supplement Table S6. Our analyses revealed

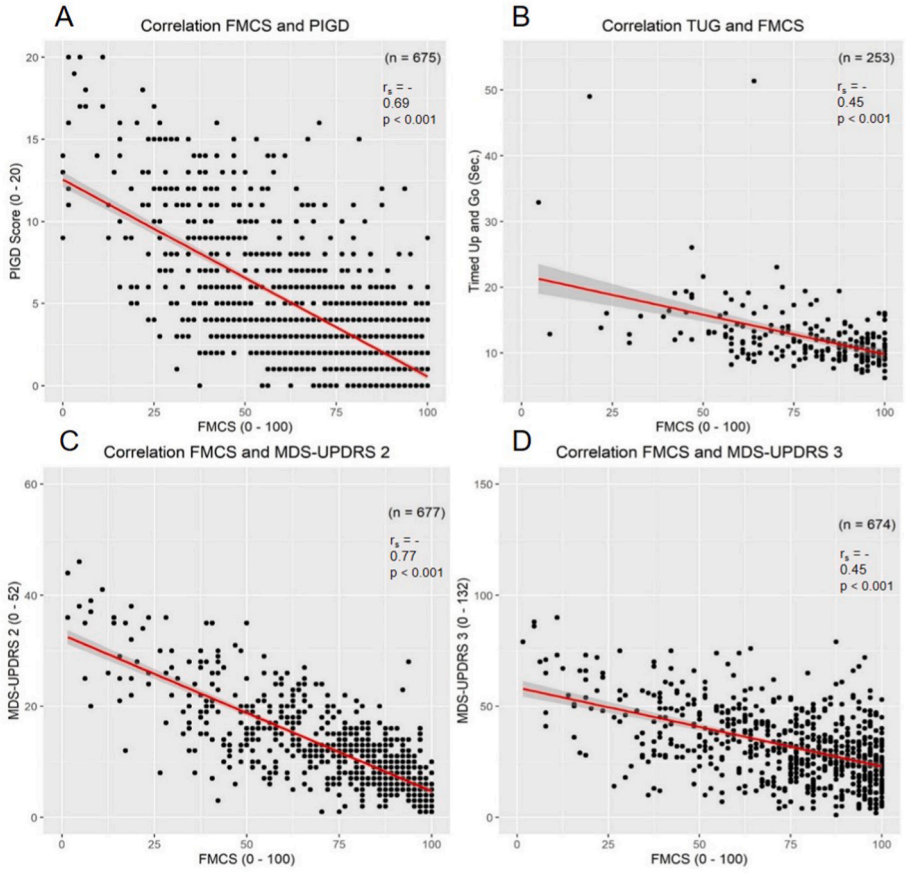

Fig. 1. Scatterplots illustrating hypothesis-testing for convergent validity.

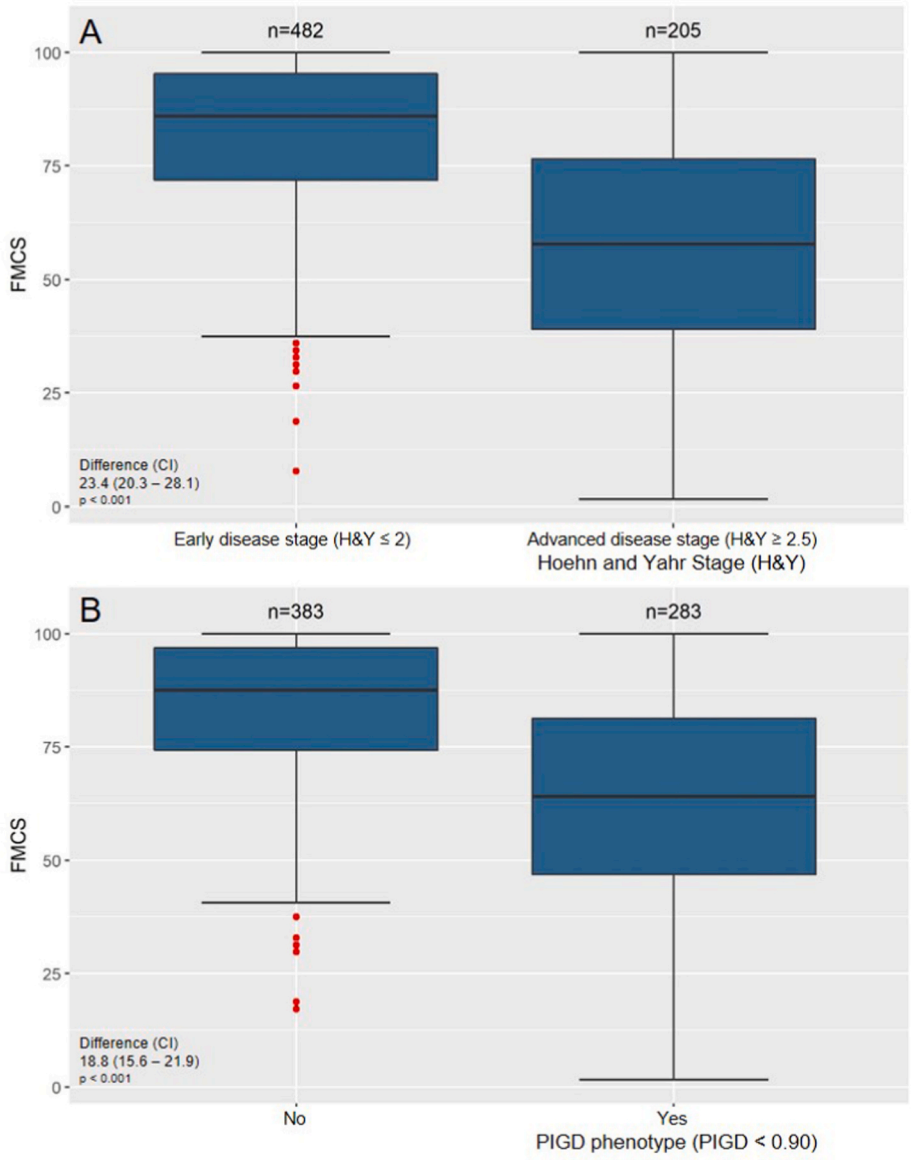

Fig. 2. Wilcoxon rank-sum tests (WRS) show statistically significant mean ranks differences for disease stages (A) and PIGD phenotype (B) (hypothesis-testing for discriminative validity – comparator groups).

the same for participants with a PIGD-phenotype compared to those without (B). Consequently, the FMCS discriminates between participants of both sets of groups. According to our sensitivity power analyses, the sample sizes of both comparator groups can detect minimum hypothetical effect sizes of 0.195 for the PIGD- and of 0.204 for the H&Y-comparator group with a probability greater than 0.80, assuming a two-sided criterion for detection that allows for a maximum Type I error rate of alpha = 0.05. Consequently, the effect sizes identified correspond to a detectable absolute r_s of 0.43 and 0.48, respectively.

As expected, the FMCS had a significantly stronger association with the subjective MDS-UPDRS II compared to the objective MDS-UPDRS III (Table 2). Notably, we identified a stronger association between the FMCS and the patient-reported BDI-I compared to between the objective TUG and the BDI-I, indicating that our instrument can differentiate between patient-reported and objective outcomes.

4. Discussion

While no current established instrument specifically assesses functional mobility through patient reports [14], multiple studies have measured patient-reported functional mobility using the subscale mobility of the PDQ-39 [17,18,20] without establishing construct validation of the subscale for this purpose. Our results in the current analyses provide support for the convergent and discriminative validity of a PDQ-39-based patient-reported functional mobility composite score (FMCS), integrating items of the frequently used and well-validated PDQ-39, which is available in several languages.

This study has some strengths and limitations. For instance, we assessed construct validity by hypothesis-testing focussing on the correlation with several similar concepts since no gold standard for patient-reported functional mobility exists. Until such a gold standard measure is developed, validated and translated the current FMCS provides a valid measure based on existing questionnaires. In this study, family members helped to complete the questionnaires if required. Our results confirm previous findings by Fleming, Cook, Nelson and Lai [30] stating that proxies scores differed from those of PwP. Consequently, the interpretation of proxy ratings needs to take this into account. Future research could investigate the feasibility of our score in patients with PDD and the time required for completion. While the COVID-19 pandemic may have led to missing data and sampling bias for the analyses involving the

Table 1
Sociodemographic and health-related characteristics of the participants (N = 736) included at baseline assessment.

Characteristics	Mean (SD)/n (%)	Min. - Max.	Median (IQR)	Missing N (%)
Sociodemographic characteristics				
Age (y.)	67.3 (10.9)	22.0–92.9	68.3 (60.2–74.7)	0 (0%)
Children (n)	1.9 (1.2)	0.0–7.0	2.0 (1.0–2.0)	2 (0.3%)
Years of Education	12.9 (4.1)	1.0–30.0	12.0 (10.0–16.0)	5 (0.7%)
Language most fluent				0 (0%)
French	212 (28.8%)			
German	118 (16.0%)			
Luxembourgish	316 (42.9%)			
Other	90 (12.2%)			
Male sex	489 (66.4%)			0 (0%)
Marital status				3 (0.4%)
Single	39 (5.3%)			
Married/Partnered	562 (76.4%)			
Divorced/Widowed	132 (17.9%)			
Retired	531 (72.1%)			9 (1.2%)
Health-related characteristics				
Hoehn and Yahr (H&Y) Disease Stages				8 (1.1%)
H&Y 1	73 (9.9%)			
H&Y 1.5	51 (6.9%)			
H&Y 2	380 (51.6%)			
H&Y 2.5	99 (13.5%)			
H&Y 3	71 (9.7%)			
H&Y 4	38 (5.2%)			
H&Y 5	16 (2.2%)			
Disease duration (y.)	5.2 (5.1)	0.0–32.3	3.5 (1.2–7.7)	46 (6.3%)
MoCA (0–30)[b]	24.6 (4.3)	5.0–30.0	25.0 (22.0–28.0)	19 (2.6%)
BDI-I (0–63)[a]	9.8 (7.2)	0.0–51.0	8.0 (5.0–14.0)	42 (5.7%)
MDS-UPDRS I (0–52)[a]	10.4 (6.9)	0.0–39.0	9.0 (5.8–14.0)	28 (3.8%)
MDS-UPDRS II (0–52)[a]	11.3 (8.3)	0.0–46.0	10.0 (5.0–15.0)	22 (3.0%)
MDS-UPDRS III (0–132)[a]	34.7 (16.4)	1.0–100.0	33.0 (23.0–45.0)	17 (2.3%)
MDS-UPDRS IV (0–24)[a]	1.6 (3.3)	0.0–16.0	0.0 (0.0–1.8)	10 (1.4%)
MDS-UPDRS-based PIGD Score (0–20)[a]	3.6 (3.8)	0.0–20.0	2.0 (1.0–5.0)	23 (3.1%)
PDQ-39 (0–100)[a]	25.2 (17.3)	0.0–82.1	21.8 (11.4–35.3)	68 (9.2%)
FMCS (0–100)[b]	73.8 (23.0)	1.6–100.0	79.7 (59.4–93.8)	46 (6.3%)

[a] Higher scores indicating more severe impairment.
[b] Higher scores indicating less severe impairment.

TUG, our sensitivity power analyses indicated the sample sizes allow us to detect the expected effect sizes. These adequate sample sizes were enabled by the well characterized Luxembourg Parkinson's study. Accordingly, all H0-hypotheses stated in the supplement were rejected in favor of the alternative hypotheses indicating a high validity of the FMCS according to Prinsen, Mokkink, Bouter, Alonso, Patrick, de Vet and Terwee [31]. Moreover, we enhanced the generalizability of our findings by analyzing data of all participants of the Luxembourg Parkinson's study including people with PD or PDD from Luxembourg and the Greater Region, who are treated and live in varying settings and environments. More specifically, the range of participants was broad, including men and women from 22 to 92 years with 1–8 children and 1–26 years of education, living from 0 to 32 years with the disease and speaking different languages. 64.9% of the participants were in disease stages H&Y 1–2, the disease stages ranged from H&Y 1 to H&Y 5. Our work provides a composite score that is available now in several languages and that allows a retrospective analysis of functional mobility in any study where PDQ-39 data have been collected [17–20]. Questionnaire completion with pencil and paper should be feasible in different settings (clinic, home care, research), and should be less costly and invasive compared to objective physical performance tests. A further advantage of the PDQ-39-based algorithm is that there is no need for PwP to complete an additional questionnaire, reducing their burden.

Table 2
Hypothesis-testing for discriminative validity – PROM versus objective measures.

H0 - Hypotheses	Absolute correlations (r_s)	Difference (CI)	Sample size	Rejected
The absolute correlation of the FMCS with the MDS-UPDRS II = the absolute correlatioan of the FMCS with the MDS-UPDRS III.	0.77 vs 0.50	β: 0.27 (0.20–0.33)	663/736	✓
The absolute correlation of the BDI with the FMCS = the absolute correlation of the BDI with the TUG.	0.55 vs 0.21	β: 0.34 (0.21–0.47)	220/253	✓
Total amount of H0 - Hypotheses that were rejected				(2/2) 100%

Note. $p < 0.001$.

In conclusion, this study has obtained comprehensive results supporting the cross-sectional construct validity of the Functional Mobility Composite Score (FMCS), an instrument assessing functional mobility through patient reports. The spreadsheet calculator in form of an R-Shiny app [32] (https://tq9t3h-ahanff.shinyapps.io/FMCS_calculator/) and sub scores by various subgroups provided in the supplement will help clinicians and other health professionals in the field to apply the FMCS in clinical practice. As the components of the FMCS have been and are widely applied, our composite score could be calculated from available data in the literature to gain insight into patient reported functional mobility in single or meta-analyses. Future work will examine the longitudinal construct validity, which, if demonstrated, will allow the FMCS to be applied in the monitoring of new treatment options addressing functional mobility.

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A-MH: 1A-C, 2A-B, 3A
CMC: 1A-C, 2C, 3A-B.
AR: 1A, 2A-C, 3B
GA: 3B
MZ, AKL: 1A, 2A, 2C, 3B,
RK: 1A-B, 2A, 2C, 3B

Detailed author roles

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Funding, Resources, Supervision, Writing – review & editing.

All authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Funding sources and conflict of interest

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The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Financial disclosures for the previous 12 months

The authors declare that there are no additional disclosures to report.

Ethical compliance statement

The studies involving human participants were reviewed and obtained a positive opinion from the National Ethics Board (CNER Ref: 201407/13). The patients/participants provided their written informed consent to participate in this study. We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this work is consistent with those guidelines.

Declaration of competing interest

This work was supported by grants from the Luxembourg National Research Fund (FNR) within the National Centre of Excellence in Research on Parkinson's disease [NCERPD(FNR/NCER13/BM/11264123)].

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.parkreldis.2023.105442.

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