



## Original article

Which type of PROMs to use in MS routine clinical care: The validity of PROMIS CAT questionnaires<sup>☆</sup>

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## ABSTRACT

**Background:** Multiple sclerosis (MS) healthcare aims to shift towards patient-centered care, in which empowered patients contribute their values in life and needs in clinical encounters. Patient-reported outcome measures (PROMs) do support the development of person-centered treatment goals and enable communication of patient's needs with healthcare providers.

**Objective:** To evaluate the construct validity of seven Patient-Reported Outcomes Measurement Information System® Computer Adaptive Tests (PROMIS CATs) that assess the domains Anxiety, Depression, Pain Interference, Fatigue, Sleep Disturbance, Physical Function, and the Ability to Participate in Social Roles and Activities in MS outpatients, and to compare the average number of items needed to obtain a PROMIS CAT domain score with the number of items in the corresponding regularly used PROMs in MS healthcare and research.

**Methods:** In this cross-sectional study PROMIS CATs and PROMs data from adult people with MS consulting the outpatient clinics of neurology or rehabilitation medicine of the MS Center Amsterdam were analysed. Construct validity of PROMIS CATs was evaluated with hypotheses testing based on predefined Spearman correlations ( $\geq 0.70$  for corresponding and  $\geq 0.50$  for related but dissimilar constructs) with HADS anxiety and depression, MSWS-12, MSIS29, EQ5D, CIS20r fatigue, AMSQ-sf. Construct validity was considered adequate when more than 75% of the formulated hypotheses were confirmed.

**Results:** Outcome data from 498 MS outpatients (median age 47.2 years [IQ 37.4–55.2]; 69% females) were available. All correlations with corresponding constructs, except for depression (Spearman's  $\rho = 0.68$ ), were  $\geq 0.70$ . All correlations with related, but dissimilar constructs were  $\geq 0.50$ . In total 94% (17/18) of our hypotheses were confirmed. Four personalized PROMIS CAT items were on average needed to complete each PROMIS questionnaire. The traditional PROMs had a fixed number of 78 items in total.

**Conclusion:** All seven PROMIS CATs demonstrated evidence for sufficient construct validity in MS outpatients. In addition, completion of PROMIS CATs required far less items than the commonly used PROMs in MS health care and research.

**Abbreviations:** AMSQ-sf, arm function in multiple sclerosis questionnaire-short form; CIS20r, checklist individual strength 20-item revised version; EQ-5D-5L, EuroQol 5 dimensions, 5 levels of answering; HADS, hospital anxiety and depression scale; MSWS-12, MS walking scale-12 items; MSIS-29, MS impact scale-29 items; PROMIS CATs, patient-reported outcomes measurement information system® computer adaptive testing; PROMs, patient-reported outcome measures.

<sup>☆</sup> Brief Title: Construct validity of Patient-Reported Outcomes Measurement Information System® Computer Adaptive Tests (PROMIS CATs) in MS

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## 1. Introduction

Over the last decades, healthcare in multiple sclerosis (MS) advocates to shift towards patient-centered care, demonstrated by incorporating patient's values and needs in life in clinical encounters and treatment decisions (Institute of Medicine (US) Committee on Quality of Health Care in America, 2001; Teisberg et al., 2020). Patient-reported outcome measures (PROMs) support the development of person-centered treatment goals and enable communication of patient needs with professionals (Khurana et al., 2017; Snyder et al., 2013; Damman et al., 2020; Ubbink et al., 2022). Current commonly used clinical outcomes in MS health care, such as Expanded Disability Status Scale (EDSS), relapse rate, and MRI characteristics, do not cover the patient perspective. Consequently, these measures do not contribute to the integration of the patient's perspective into the process of shared decision making.

Worldwide, there are several initiatives to facilitate the regular use of PROMs in medical specialist care, including care for people with MS (e. g., neurology and rehabilitation medicine) (Oude Voshaar et al., 2023; Brichetto and Zaratin, 2020). In 2019, the global Patient Reported Outcome for Multiple Sclerosis (PROMS) Initiative was launched. This multi-stakeholder and multidisciplinary initiative on patient-generated health data aims to provide a unified vision on the shared use of valid and reliable patient-reported outcomes for MS (Brichetto and Zaratin, 2020; Zaratin et al., 2022; Zaratin et al., 2024; Parciak et al., 2024). The Multiple Sclerosis Data Alliance project, an initiative that harmonized real-world MS data registries globally, found that besides a symptom checklist and an observable symptom severity score, only a few PROMs are included in some MS registries (Geys et al., 2021; Parciak et al., 2024; Zaratin et al., 2024). In the S.O.S.MS project (Daniels et al., 2023), a Standard Outcome Set for Multiple Sclerosis has been developed, consisting of fourteen outcomes regarding disease activity ( $n = 3$ ), symptoms ( $n = 4$ ), functional status ( $n = 6$ ), and quality of life ( $n = 1$ ) (Daniels et al., 2023). In addition, MS core outcome sets exist to evaluate exercise therapy (Paul et al., 2014) and rehabilitation programs (Cohen et al., 2015; Potter et al., 2014), to use in health technology assessment studies (value-based contracting) ((Swart et al., 2019), and in pharmacological trials (van Munster and Uitdehaag, 2017; Ciani et al., 2023).

The Patient-Reported Outcomes Measurement Information System (PROMIS®) using computerized adaptive testing (CAT) is one of the proposed sets of generic PROMs to measure the health condition of people consulting healthcare professionals (Cella et al., 2007; Oude Voshaar et al., 2023). PROMIS® measures are developed with modern item response theory methods resulting in hierarchically calibrated set of questions in so-called PROMIS item banks, use a common T-score metric, and provide population norms. In a CAT, after a fixed starting question, the computer selects for each individual patient follow-up questions from the item bank based on answers to the questions already administered (Bjorner et al., 2007). Most PROMIS measures evaluate the past seven days. The PROMIS Physical Function uses no recall period and asks about the actual function.

In MS healthcare, PROMIS® CAT is a relatively novel measurement method which might have several advantages compared with traditional, non-adaptive PROMs such as the MS Impact Scale (MSIS-29) or MS Walking Scale (MSWS-12) (Hobart et al., 2001, 2003). PROMIS CATs provide standardized unidimensional tools that capture health outcomes relevant to a patient's daily functioning. Since all PROMIS measures are generic, they allow comparison of scores across diseases and comparison with the general population. Unlike traditional MS-specific PROMs, generic patient-reported outcomes can be easily shared across hospital departments a patient visits, reducing patient burden. Moreover, each question that is selected from the item bank of a specific PROMIS domain is relevant to the patient, further reducing patient burden. Each PROMIS CAT covers a wide range of functioning with limited floor and ceiling effects, which make these PROMs applicable to all patients with MS, regardless of age, cultural background, or disease status. Validity

and reliability of (non-adaptive) PROMIS short forms have been investigated in MS (Amtmann et al., 2018). However, PROMIS® CATs were validated in only one study in people living with MS (Senders et al., 2014).

Knowledge of the construct validity can support considerations about which PROMs best fit routine medical care in MS. Moreover, improving the understanding of PROMIS scores as compared to existing MS PROMs might facilitate interpretation in the clinical setting as well as research. The aim of this study is to investigate the construct validity of seven PROMIS CATs assessing Physical Function, Pain Interference, Fatigue, Sleep Disturbance, Anxiety, Depression, and the Ability to Participate in Social Roles and Activities. PROMIS CATs are compared with MS-specific and non-specific PROMS that have been validated in MS and currently used in Dutch outpatient clinics of neurology and rehabilitation medicine. Furthermore, we compare the average number of items needed to obtain a PROMIS CAT domain score with the number of items in the corresponding traditional questionnaires.

## 2. Materials and methods

### 2.1. Participants

Adult people with MS, consulting the neurology or rehabilitation medicine outpatient clinics of the MS Center Amsterdam, Amsterdam UMC, were digitally approached two weeks prior to the consultation date, to fill in a set of disease-specific PROMs and PROMIS-CATs. The questionnaires were sent via the electronic medical record software system 'Epic systems corporation' (EPIC), via the patient portal 'MyChart' between August 2020 and July 2023.

### 2.2. Ethics

This cross-sectional study was conducted within the framework of the Dutch law Healthcare Quality, Complaints and Disputes Act. This law obligates healthcare providers to continuously monitor, control and improve their quality of care (Government of The Netherlands, 2024). Within the medical ethical permission of the Amsterdam MS cohort (2020.269), patients provided written informed consent for using their data for research purposes.

### 2.3. PROMIS CATs

Seven Dutch-Flemish PROMIS CATs were administered via the electronic patient portal: PROMIS CAT Depression (v1.0), PROMIS CAT Anxiety (v1.0), PROMIS CAT Fatigue (v1.0), PROMIS CAT Pain Interference (v1.1), PROMIS CAT Sleep Disturbance (v1.0), PROMIS CAT Physical Function (v1.2), and PROMIS CAT Ability to Participate in Social Roles and Activities (v2.0) (Table 1) (Terwee et al., 2014). Default PROMIS CAT software included in the Assessment Center Application Programming Interface (API) distributed by HealthMeasures, was implemented in the electronic medical record system EPIC in Amsterdam UMC.

Each PROMIS CAT utilizes an item bank (i.e., a large set of questions), developed using item response theory (IRT) models, that are administered as computerized adaptive tests (CATs). In a CAT, the starting item is the item with the highest information value for the average level of the domain in the general population. Follow-up questions are adapted real-time to each person's ability, resulting in questions that are likely more relevant to that person. Therefore, the number and type of questions varies from person to person, depending on the severity of symptoms or the level of ability and the consistency of the answers. In this study, the CAT stopped when a standard error (SE) of 3.0 on the T-score metric was reached or when a maximum of 12 items per CAT was answered by the participant.

All PROMIS items have five response options, ranging from 'never' to 'always' or from 'not at all' to 'very much'. PROMIS CATs are presented

**Table 1**

PROMIS CAT characteristics and outcomes in MS outpatients.

PROMIS CAT	Number of items in item bank	Respondents (n)	Number of CAT items completed median [range]	Respondents needing 4 items (%)	Median scores [IQ]
PROMIS CAT Depression (v1.0)	28	413	4 [4–12]	69.5	51 [46–59]
PROMIS CAT Anxiety (v1.0)	29	409	4 [4–12]	72.4	54 [49–60]
PROMIS CAT Fatigue (v1.0)	95	416	4 [4–12]	87.5	55 [48–63]
PROMIS CAT Sleep Disturbance (v1.0)	27	412	4 [4–12]	55.1	50 [44–56]
PROMIS CAT Pain Interference (v1.1)	40	251	4 [4–12]	54.2	55 [39–62]
PROMIS CAT Physical Function (v1.2)	121	317	4 [4–12]	82.2	41 [35–49]
PROMIS CAT Ability to Participate in Social Roles and Activities (v2.0)	35	332	4 [4–12]	78.3	44 [39–53]

as T-scores, where 50 (SD 10) represents the average score of the US general population. (Cella et al., 2010) Average T-values of the Dutch population are also around 50 for most domains, except for Pain Interference (T-score 55) (Terwee and Roorda, 2023; Dutch-Flemish PROMIS National Center, 2024). Higher T-scores indicate more of the construct (e.g., a higher PROMIS Depression score means more depression, a higher PROMIS Physical Function score means more [better] physical function).

#### 2.4. MS-specific and other PROMs

To compare the PROMIS CATs with commonly used PROMs, the following six validated PROMs were included in this study (Table 2).

The Hospital Anxiety and Depression Scale (HADS) contains 7 items focused on depression (HADS-depression) and 7 items focused on anxiety (HADS-anxiety). The higher the total score the worse the mental health status (Honarmand and Feinstein, 2009; Jerković et al., 2021).

The Checklist Individual Strength (CIS20r) includes 20 questions about fatigue severity, and the impact of fatigue on physical activity, motivation and concentration (Beurskens et al., 2000). In this study only the CIS20r fatigue subscale with 8 items was used (Beckerman et al., 2020).

The MS Walking Scale-12 (MSWS-12) contains 12 questions regarding walking abilities. The score ranges from 12 to 60, with higher scores indication higher impact of MS on walking abilities (Hobart et al., 2003). Prior to the MSWS-12, patients who were completely unable to walk were detected by a 6-point question about their walking ability. The MSWS-12 was automatically skipped for these patients. This 6-point question replaces the first screening question of the MSWS-12 (i.e. If you cannot walk at all, please tick this box).

The MS Impact Scale (MSIS-29) contains 29 questions regarding the impact of MS on daily life activities (Hobart et al., 2001). Twenty questions focus on physical health, and nine questions focus on psychological health. The higher the total score the higher the impact of MS on daily life activities.

The 10-item short-form of the Arm Function in Multiple Sclerosis Questionnaire provides an efficient way to measure arm and hand function in MS patients. The higher the score the higher the impact of

MS on arm and hand functioning (Luijten et al., 2018; van Leeuwen et al., 2017).

The EQ-5D-5L focuses on five domains, i.e., mobility, self-care, usual daily activities, pain/discomfort, and anxiety/depression (EuroQol Research Foundation, 2021). Scores are converted to a utility score using the Dutch Tariff (Versteegh et al., 2016). Total utility varies between 0 and 1, with a low utility indicating a poor health status.

#### 2.5. Clinical characteristics

The most recently registered type of MS, date of MS onset, date of diagnosis, and EDSS at the clinical encounter were retrieved from the electronic research database of the Amsterdam MS Cohort.

#### 2.6. Construct validity

The construct validity of PROMIS CATs was evaluated with hypotheses testing based on expected correlations between the PROMIS CAT domains and the other (MS-specific) PROMs. Hypotheses were formulated prior to the analyses. We expected strong correlations (Spearman's rho ( $\rho$ )  $\geq 0.7$ ) between PROMIS CATs and measures that assess the same construct (i.e., CIS20r fatigue, HADS anxiety, HADS depression), and moderate correlations ( $\rho = 0.5$ – $0.7$ ) between PROMIS CATs and largely related questionnaires. (See supplementary materials) Construct validity of PROMIS CATs was considered sufficient if 75% or more of the correlations were in accordance with the hypotheses (Prinsen et al., 2018).

#### 2.7. Data analysis

Although part of the outpatients repeatedly filled in a set of PROMs between August 2020 and July 2023, only cross-sectional data (i.e., the same time point for PROMs and PROMIS CATs) were used. Hereto, the first most completed MS PROMS patient record was selected for analysis. The electronic platform to complete PROMs did not allow for any missing item values within a PROM. If patients left a PROMIS CAT question open, a next question from the item bank was asked. Due to non-normally distributed data, Spearman correlation coefficients with

**Table 2**

Traditional PROMs characteristics and outcomes in MS outpatients.

PROMs (subscales)	Fixed number of questions	Maximal range of scores	Respondents (n)	Median scores [IQ]
HADS depression	7	0–21	412	3 [1–7]
HADS anxiety	7	0–21	412	4 [2–7]
CIS20R fatigue	8	8–56	410	34 [21–44]
MSIS-29 physical	20	20–100	393	38 [26–56]
MSIS-29 psychological	9	9–45	393	16 [12–22]
MSWS-12	12	12–60	367	27 [14–42]
AMSQ-SF	10	10–60	424	11 [10–18]
EQ-5D-5L index	5	0–1	402	0.81 [0.66–0.89]

EQ-5D-5 L item scores are presented in Table 3.

**Table 3**

Sociodemographic and clinical characteristics of the total MS study population ( $n = 498$ ).

Characteristic	N	%
<b>Gender</b>		
Female	343	68.9
Male	155	31.1
<b>Age*</b> (yr)	47.2	[37.4–55.2]
<b>MS duration*</b> (yr) ( $n = 407$ )	11.9	[5.1–17.5]
<b>MS type</b>		
Primary progressive	31	6.2
Relapsing Remitting	327	65.7
Secondary Progressive	37	7.4
Type of MS not defined in registry database	103	20.7
<b>EDSS*</b> ( $n = 303$ )	3.5	[2.0–4.5]
<b>Walking ability</b> ( $n = 388$ )		
Cannot walk	21	4.2
Extremely limited	28	5.6
Limited quite a lot	63	12.7
Moderately limited	51	10.2
A little limited	88	17.7
Not at all limited	137	27.5

\* Median scores and interquartiles.

their 95% confidence intervals (95%CI) were calculated using SPSS statistical software, version 28.0.1.1 (IBM Corp., Armonk, NY, USA).

### 3. Results

#### 3.1. Participants

In total, 498 participants with a median age of 47.2 years [IQ 37.4–55.2] were included in current analyses. About 69% of participants were female. Nearly 10% of the participants reported that they could not walk or had extremely limited walking ability, whereas 27.5% had no walking limitation. Sociodemographic and clinical characteristics of the participants are shown in Table 3.

#### 3.2. PROMIS CATs and PROMs

Sample sizes for individual scales varied between 251 and 424 individuals (Tables 1 and 2).

At the group level, average PROMIS CAT scores deviated from the

mean population T-score of 50, except for PROMIS CAT Sleep Disturbance with median score of 50 [IQ: 44–56] and PROMIS CAT Depression (median 51, IQ: 46–59). On all seven PROMIS CATs, the majority of patients needed four items only to complete each questionnaire (Table 1).

The average scores on the HADS depression and HADS anxiety were low (<7). Descriptives of CIS20R fatigue, MSIS-29 physical, MSIS-29 psychological, MSWS-12, AMSQ-SF, and EQ-5D-5 L index are shown in Table 2. The total set of traditional MS PROMs that patients had to fill in, consisted of 78 items (Table 2).

#### 3.3. Construct validity

Table 4 shows the Spearman's rho ( $\rho$ ) for PROMIS CATs with (MS-specific) PROMs measuring the same overall construct. All correlation coefficients, but depression with a rho of 0.68, were  $\geq 0.70$  (Table 4). All questionnaires that had related, but dissimilar constructs showed a correlation of  $\geq 0.50$  (Table 5). Construct validity was considered adequate as 17/18 (94%) of the results were in accordance with our hypotheses.

### 4. Discussion

This MS PROMS study investigated the correlations of scores of PROMIS CATs with commonly used MS-specific and generic PROMs. All seven PROMIS CATs, assessing Physical Function, Pain Interference, Fatigue, Sleep Disturbance, Anxiety, Depression, and the Ability to Participate in Social Roles and Activities, demonstrated evidence for sufficient construct validity in people with MS at the MS outpatient clinics neurology and rehabilitation medicine. High correlations of  $-0.88$  between PROMIS CAT Physical function and MSWS-12, and  $-0.80$  between PROMIS CAT - Participation and MSIS-29 physical further support the construct validity of PROMIS CATs.

As expected, completion of PROMIS CATs required far less items than the commonly used PROMs. Four personalized PROMIS CAT items were on average needed to complete as compared to e.g., the 20 items of the CIS20r, 29 items of the MSIS-29, 12 items of the MSWS-12, and 14 items of the HADS to measure anxiety and depression.

Our results are consistent with the results of a previous study, in which also strong correlations (0.67–0.87) between PROMIS CATs for

**Table 4**

Construct validity of PROMIS CATs with PROMs measuring the same construct, of which strong correlations ( $\rho \geq 0.7$ ) were expected.

PROMIS CAT vs traditional PROM	Spearman's rho	95% CI
PROMIS CAT Depression - HADS depression	0.68	0.62 - 0.74
PROMIS CAT Depression - MSIS-29 psychological	0.73	0.68 - 0.78
PROMIS CAT Depression - EQ-5D-5 L item anxiety/depression	0.75	0.70 - 0.79
PROMIS CAT Anxiety - HADS anxiety	0.75	0.70 - 0.79
PROMIS CAT Anxiety - MSIS-29 psychological	0.74	0.69 - 0.78
PROMIS CAT Anxiety - EQ-5D-5 L item anxiety/depression	0.70	0.64 - 0.75
PROMIS CAT Fatigue - CIS20r fatigue	0.83	0.80 - 0.86
PROMIS CAT Pain Interference - EQ-5D-5 L item pain	0.76	0.70 - 0.81
PROMIS CAT Physical Function - MSIS-29 physical	-0.86	-0.89 to -0.83
PROMIS CAT Ability to Participate in Social Roles and Activities - EQ-5D-5 L item daily activities	-0.74	-0.79 to -0.68

**Table 5**

Construct validity of PROMIS CATs with largely related PROMs, of which moderate correlations ( $\rho \geq 0.5$ ) were expected.

PROMIS CAT vs largely related PROM	Spearman's rho	95% CI
PROMIS CAT Depression - HADS anxiety	0.70	0.64 - 0.75
PROMIS CAT Anxiety - HADS depression	0.60	0.53 - 0.66
PROMIS CAT Sleep Disturbance - CIS20r fatigue	0.52	0.44 - 0.59
PROMIS CAT Sleep Disturbance - MSIS-29 psychological	0.55	0.47 - 0.62
PROMIS CAT Physical Function - AMSQ-SF	-0.68	-0.74 to -0.62
PROMIS CAT Physical Function - MSWS-12	-0.88	-0.91 to -0.85
PROMIS CAT Ability to Participate in Social Roles and Activities - MSIS-29 physical	-0.80	-0.83 to -0.75
PROMIS CAT Ability to Participate in Social Roles and Activities - MSIS-29 psychological	-0.67	-0.73 to -0.61



Depression, Anxiety, Pain, Fatigue and Physical Function, and corresponding PROMs were found in a convenience sample of 133 patients with MS (Senders et al., 2014).

#### 4.1. Clinical practice

In this study we used MS PROMs data that was gathered in an outpatient clinical care setting where patient-reported outcomes can influence individual care. While PROMs and PROMIS CATs have great potential to improve and guide joint clinical decision making together with patients, currently their use might be hindered by limited provider understanding of how to use and to interpret PROMs and PROMIS CATs (Reitzel et al., 2022). Not all physicians are equally engaged with the concept of patient-centered care, effective patient engagement, shared decision making and the routine use of generic and disease-specific PROMs (Lim et al., 2022; Churrua et al., 2021). To better understand the value of using PROMs in daily clinical practice, it is useful to clearly distinguish the purpose of using PROMs: 1) for diagnostic or screening/early identification (discriminatory) purposes, 2) individual prognosis (predictive purposes), or 3) patient monitoring and therapy evaluation (evaluative purposes) (Guyatt et al., 1992). For example, for symptom profiling, PROMIS CAT measures can easily be used to quickly assess symptom levels in an individual and compare visualized outcomes with reference values in the general population (van Muilekom et al., 2021).

Practical barriers to the routine use of PROMs and PROMIS CAT may occur when the correct digital infrastructure is not in place or when their use is disruptive to normal work routines (Reitzel et al., 2022; D'Amigo et al., 2019). It is labour-intensive and costly to build in PROMs (including PROMIS CAT) and their scoring algorithms into the electronic health records of patients (Groenewegen et al., 2024). Improvements regarding the individualized or tailored selection of PROMs to be sent to patients, the timely monitoring of patient compliance, and the automatic transfer of outcomes to referral or discharge letters deserve further attention. Obviously, the clinical use of PROMs requires careful consideration in people with MS with physical or cognitive disabilities, reduced health or technology literacy (Lans et al., 2023), and different native languages (Edwards et al., 2023).

To facilitate the implementation of PROMIS CATs, several crosswalk tables are available that link scores from known PROMs to PROMIS scores for depression, and fatigue, respectively, to compare PROMIS scores with historically collected PROM data (Kim et al., 2017; Noonan et al., 2012). Although PROMIS crosswalk tables seem applicable to different populations (Tang et al., 2022), they are only accurately applicable for group-level analyses with a sample size greater than 150 or larger. The conversion of scores is insufficiently accurate to use in clinical practice in individual patients or in small research studies (Noonan et al., 2012). Recently, MS-specific PROMIS short forms for respectively physical function and fatigue were developed with input from MS patients and clinicians (Kamudoni et al., 2022). Based on current findings and the tendency to harmonize the use of generic PROMs/PROMIS CAT across medical conditions we question whether the development of MS-specific PROMIS short forms is desirable. Besides, physical function and fatigue concern generic health constructs.

People with MS believe that the use of PROMs leads to increased patient involvement and communication with their clinician (Westergaard et al., 2022). With an average of only four questions per domain to answer, as this study showed, people with MS may perceive PROMIS CATs as less burdensome compared to commonly used PROMs. A limitation of PROMIS CATs is that they can only be completed digitally and require a real-time internet connection. In this study we had no information about MS patients that were not subscribed to their patient portal.

#### 4.2. Minimal important change

For the monitoring of individual patients over time, the minimal important change (MIC) value of outcomes is essential. The MIC is a threshold for a minimal within-person change over time above which patients (and clinicians) consider the change as meaningful. Patients have their individual threshold of what they consider a minimal important improvement or deterioration (de Groot et al., 2006). A systematic review of PROMIS MIC values showed that published MIC estimates for PROMIS measures vary widely (Terwee et al., 2021). For non-surgical interventions, a MIC value of 2–6 T-points, covering about two thirds of the published MIC values, was assumed reasonable. The systematic review of Terwee et al. (2021) did not allow for PROMIS construct-specific or population-specific recommendations. To gain more insight in the meaning of PROMIS change scores in individuals with MS, further clinical studies are needed to examine whether MIC values differ across PROMIS scales for improvement or deterioration over time (de Groot et al., 2006). Our cross-sectional MS PROMS data did not allow analyses of other relevant measurement properties such as the MIC and responsiveness.

#### 4.3. Reference values general population

The development and calibration of PROMIS outcome measures utilized a large sample (>20,000) of the US general population (Cella et al., 2010; Lui et al., 2010). Apart from PROMIS Pain Interference (54.9), reference values from the Dutch general population are comparable to the T-scores of 50 of the US general population (i.e. PROMIS Anxiety 49.9, PROMIS Depression 49.9, PROMIS Physical Function 49.8, and PROMIS Ability to Participate in Social Roles and Activities 50.6) (Elsman et al., 2022; Terwee and Roorda, 2023).

#### 4.4. Integrated set of PROMIS CATs

Since MS affects many aspects of functioning, it can be informative to examine multiple patient-reported outcomes simultaneously to understand the eventual clustering of symptoms and the full impact of the disease on an individual's functioning and overall health and wellbeing. In personalized care, it is important that personal and environmental factors are explicitly being considered. The International Classification of Functioning (ICF) framework can be used to monitor the dynamic interaction between a person's health condition, the environmental factors, and personal factors (contextual factors) such as gender, race, age, education, and individual adaptation style (WHO, 2001; Dekker and de Groot, 2018; van der Veen et al., 2023). Our results suggest that an integrated set of PROMIS CATs could be efficiently used for simultaneous measurement of patient-relevant outcomes in people with MS. The integrated collection of patient-relevant information covering symptoms, daily functioning and activities, societal participation, and wellbeing issues, together with a careful dialogue with patients during the outpatient consultation will contribute to improved healthcare outcomes in areas that matter the most to people living with MS (Whitty et al., 2020).

#### 4.5. Study limitations

The following study limitations should be notified. MS disease characteristics were automatically retrieved from the medical files. Linking the MS PROMS database of this study to the research database of Amsterdam MS Cohort resulted in several missing MS characteristics.

For PROMIS CAT sleep disturbance, we had no direct comparator measure included. However, PROMIS CAT sleep disturbance correlated moderately with CIS20r fatigue and MSIS-29 psychological, providing some supportive evidence for the construct validity of this questionnaire. Although there are more PROMIS CATs developed and validated, such as the PROMIS CAT Upper Extremity, these questionnaires are not

yet included in our electronic measuring battery. Similar research in people with MS into the construct validity of the PROMIS CAT Upper Extremity and the AMSQ CAT, which was also developed using IRT models, or the 10-item short form of the AMSQ could be conducted (Luijten et al., 2018; van Leeuwen et al., 2017). In order to use PROMIS CAT Depression, Anxiety and Fatigue as screening instruments, research into their diagnostic accuracy is recommended.

For this project, we used a large set of PROMIS CATs and traditional PROMS that were administered in a fixed order. Although patients were allowed to use several days to complete all questionnaires, the possibility of order effects, e.g., due to respondent fatigue cannot be excluded. However, the experiences of this clinical study allow us to significantly reduce the number of questionnaires.

In this study we had no information about MS patients who were not subscribed to their patient portal, or patients who did not respond to the invitation of their clinician to fill in the questionnaires.

The feasibility and selection bias of digital data collection via patient portals of electronic health records requires further investigation.

## 5. Conclusion

This study investigated the comparability of scores of PROMIS CATs with well-known MS-specific and generic PROMs. All seven PROMIS CATs assessing physical function, pain interference, fatigue, sleep disturbance, anxiety, depression, and the ability to participate in social roles and activities, demonstrated evidence for sufficient construct validity in people with MS at the MS outpatient clinics neurology and rehabilitation medicine. PROMIS CATs enable efficient measurement, because patients have to fill in less items than the commonly used PROMs in MS healthcare.

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## CRediT authorship contribution statement

**Heleen Beckerman:** Writing – review & editing, Writing – original draft, Supervision, Methodology, Formal analysis, Conceptualization. **Isaline C.J.M. Eijssen:** Writing – review & editing. **Roos Walraven:** Writing – review & editing, Writing – original draft, Investigation, Formal analysis. **Eva M.M. Strijbis:** Writing – review & editing. **Caroline B. Terwee:** Writing – review & editing. **Bernard M.J. Uitdehaag:** Writing – review & editing. **Vincent de Groot:** Writing – review & editing. **Brigit A. de Jong:** Writing – review & editing, Software, Resources, Project administration, Methodology, Conceptualization.

## Declaration of competing interest

Heleen Beckerman, Isaline C.J.M. Eijssen, Roos Walraven and Vincent de Groot declare that there is no conflict of interest.

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Caroline B. Terwee is founder and representative of the Dutch-Flemish PROMIS National Center, a registered partner of the US PROMIS National Institutes of Health.

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There is no commercial entity relevant for potential conflicts.

## Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.msard.2025.106320.

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