Monitoring Multiple Sclerosis in Specialty Pharmacy: A Narrative Review of Services, Outcomes, & Patient-Reported Outcome Measures

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Background

- Monitoring disease stability in multiple sclerosis (MS) is challenging, particularly with progression independent of relapse activity (PIRA) and smoldering MS, where gradual decline may not be captured during routine visits and can be further obscured by infrequent assessments and limitations of standard clinical measures.
- Specialty pharmacies (SPs) support people with MS (PwMS) through medication access, education, refill coordination, and adherence and safety monitoring, enabling frequent patient touchpoints; however, tools to capture meaningful symptom changes within SP workflows remain unclear.

Objective

To evaluate the evidence supporting SP services and patient outcomes in MS, and to assess the feasibility, relevance, and actionability of patient-reported outcome measures (PROMs) within SP workflows as tools for earlier identification of symptom changes and disease progression

Methods

Study Design

A targeted narrative review was conducted to synthesize published evidence on SP services, outcomes, and monitoring practices for PwMS. Relevant literature was obtained by searching PubMed using key terms, and articles through December 2025 were included.

Methods & Evidence Identification

- Key terms were related to multiple sclerosis, specialty pharmacy, access, adherence, pharmacist interventions, and monitoring measures, including patient-reported outcome measures.

Searches of PubMed and major SP conference portals using key terms → Titles and abstracts screened for relevance to SP services, outcomes, or monitoring practices in MS → 46 full-text articles and conference abstracts reviewed and data extracted → 28 directly describing SP services or programs included in the narrative synthesis

Evidence Synthesis

- Evidence was organized by service domain, outcomes, and monitoring approaches.
- PROMs were evaluated based on feasibility (brief, low-burden, suitable for administration within SP workflows), relevance (coverage of key MS symptom and quality-of-life domains), and actionability (ability to support real-time interpretation and pharmacist intervention).

Results

Figure 1: Summary of Services Provided by SPs to Support PwMS

Medication Access & Affordability

- **Facilitate timely medication access** through benefits investigations, prior authorization support, and coordination within limited distribution networks
- **Identify and secure financial assistance** (e.g., manufacturer programs, independent grants, etc.) to reduce patient out-of-pocket costs
- **Improve access outcomes**, including faster time-to-therapy initiation and high rates of successful treatment acquisition

Medication Education, Distribution, & Adherence

- **Provide patient education on medication use,** administration, and storage, reinforcing safe and effective therapy
- **Coordinate dispensing and establish** structured refill processes to maintain consistent treatment access
- **Support high adherence and persistence** through ongoing patient engagement and proactive refill management

Medication Monitoring & Intervention

- **Conduct routine monitoring for safety, tolerability, and adherence with structured patient assessments at regular touchpoints**
- **Identify issues and intervene through medication education, safety management, and coordination with providers**
- **Document and address patient-reported concerns, though effectiveness monitoring is often limited by use of simple, single-item measures**

Table 1: PROM Symptom Domains

	Symptom Domains									
PROM	Physical Function & Mobility	Fatigue & Sleep	Pain & Sensory	Vision	Mental & Emotional Health	Cognition	Bowel & Bladder	Sexual Health	Feelings of Wellbeing & Community	Overall Quality of Life
EQ-5D	X		X		X				X	
FSS		X								
MSIS-29	X				X					
MSPS	X	X	X	X		X	X			
MSQLI		X	X	X	X	X	X	X	X	X
MSQoL-54	X	X	X		X	X		X	X	X
MSWS-12	X									
Neuro-QoL	X	X			X	X			X	X
PDDS	X									
PROMIS	X	X	X		X	X			X	X
SF-36	X		X		X				X	X

PROM Abbreviations: EQ-5D = EuroQol Five-Dimensional Questionnaire, FSS = Fatigue Severity Scale, MS = Multiple Sclerosis, MSIS-29 = Multiple Sclerosis Impact Scale, MSPS = Multiple Sclerosis Performance Scales, MSQLI = Multiple Sclerosis Quality of Life Inventory, MSQoL-54 = Multiple Sclerosis Quality of Life, MSWS-12 = Multiple Sclerosis Walking Scale, Neuro-QoL = Quality of Life in Neurological Disorders, PDDS = Patient-Determined Disease Steps, PROMIS = Patient-Reported Outcomes Measurement Information System, SF-36 = Short Form Health Survey

Results Cont.

Across identified PROMs (Tables 1–2), limitations in administration time (feasibility), domain coverage (relevance), and scoring complexity or interpretability (actionability) prevented any single tool from meeting all three criteria.

Table 2: PROM Characteristics

PROM	Number of Items	Recall Period	Response Format	Scoring Method[a]	Scoring Result	Estimated Completion Time[b]	MS Specificity
EQ-5D	5	"Today"	Mixed	Simple	Single Value	Quick	No
FSS	9	1 week	Likert	Simple	Single Value	Quick	No
MSIS-29	26	2 weeks	Likert	Complex	Multiple Values	Medium	Yes
MSPS	8	"Today"	Ordinal Scale	Simple	Single Value	Quick	Yes
MSQLI	81-138	4 weeks	Mixed	Complex	Multiple Values	Long	Yes
MSQoL-54	54	Mixed	Mixed	Complex	Multiple Values	Long	Yes
MSWS-12	12	2 weeks	Likert	Simple	Single Value	Short	Yes
Neuro-QoL	Varies	1 week	Likert	Complex	Single Value	Medium	No
PDDS	1	"Today"	Ordinal Scale (0-8)	Simple	Single Value	Quick	Yes
PROMIS	Varies	1 week	Likert	Mixed	Single Value	Medium	No
SF-36	36	4 weeks	Likert	Complex	Multiple Values	Short	No

[a] Simple = Scoring can be completed using basic functions such as summing scores; Complex = Scoring requires multiple calculations or an external algorithm; [b] Q = Quick: <6 minutes, S = Short: 6-10 minutes, M = Medium: 11-20 minutes, L = Long: >20 minutes

Discussion & Conclusion

- Most available evidence, which is largely from health-system specialty pharmacies (HSSPs), indicates that SPs play a critical role in longitudinal MS care, supporting access, adherence, and safety through frequent patient interactions.
- Despite these contributions, practical tools to monitor symptom change or early progression are limited, and existing PROMs often fall short in feasibility, relevance, and actionability for SP workflows.
- Brief (≤10 minutes) SP-aligned PROMs, curated composites of validated items, or structured domain-based screening approaches may support earlier identification of concerning changes and improve care coordination with neurology teams.

References

Wash A, Hickman A, Skrtic A, Lopez-Medina AI, Fitzpatrick C, Geyer M, Mourani J. Optimizing multiple sclerosis care through specialty pharmacy: current practices, monitoring strategies, and PROM utilization. (Manuscript submitted for publication).

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