

Patient reported outcome measures of upper limb function in multiple sclerosis: A critical overview

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**Patient reported outcome measures to measure the upper limb function in Multiple Sclerosis: a critical overview.**

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3 **Patient reported outcome measures to measure the upper limb function in**  
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5 **Multiple Sclerosis: a critical overview.**  
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10 Lamers Ilse<sup>1,2</sup> PhD and Feys Peter<sup>1</sup> PhD  
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15 <sup>1</sup> *REVAL Rehabilitation Research Center, Faculty of Rehabilitation Sciences, Hasselt*  
16  
17 *University, Belgium*  
18

19  
20 <sup>2</sup> *Rehabilitation and MS center, Overpelt, Belgium*  
21  
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34 Ilse Lamers  
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36  
37 REVAL-BIOMED, Hasselt University  
38

39  
40 Martelarenlaan 42  
41

42  
43 3500 Hasselt, Belgium  
44

45  
46 +3211286939  
47

48  
49 Email: ilse.lamers@uhasselt.be  
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## **Patient reported outcome measures to measure the upper limb function in Multiple Sclerosis: a critical overview.**

Nowadays, the upper limb function of patients with multiple sclerosis (MS) is increasingly acknowledged as important as the upper limb disability has an impact on the performance of daily life activities and reduces the quality of life. In order to investigate whether an intervention strategy (drugs therapy and rehabilitation) has an impact on the upper limb disability, outcome measures with good psychometric properties are warranted. In a topical review on upper limb assessment<sup>1</sup>, we concluded that there is no single outcome measure available that covers the entire range of upper limb functionality as defined by International Classification of Functioning (ICF), and is applicable with sensitivity across different upper limb disability levels. The NHPT is however likely one of the best proxies for measuring upper limb capacity in MS.<sup>2</sup>

In recent years, patient-reported outcome measures (PROMs) are acknowledged as an important part in the upper limb assessment in MS as they provide more information about the difficulties MS patients experience when performing activities of daily life (ADL) with their upper limb, the latter being considered as the ultimate goal of upper limb treatment. Different studies<sup>3,4</sup> have indicated that scores on capacity measures (e.g. Nine Hole Peg Test or Action Research Arm test) are not highly related to PRO meaning that they measure different concepts. It was even demonstrated that some MS patients with (almost) normal scores on capacity measures, report upper limb disability affecting their ADL performance. Therefore, we recommend the inclusion of PROMs in clinical trials and practice, and hypothesize it may be even more sensitive to detect activity limitations in early MS stages than unilateral capacity tests.

To date, different PROMs developed for other neurological disease or disease causing upper limb disability are being used to assess the upper limbs disability in MS. These PROMs

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3 have a lot in common such as the activities included in the items of the questionnaire (e.g.  
4 washing hand, using a knife, button clothes, turning a key, open a jar or bottle) but also some  
5 differences such as the question asked and the scoring method. The most frequently used  
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7 PROMs in intervention and cross-sectional studies so far are the ABILHAND<sup>5</sup> and Manual  
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9 Ability Measure-36 (MAM-36)<sup>6</sup>. Both PROMs measure the perceived ease or difficulty that a  
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11 person may experience when performing ADL regardless of which upper limb they use. There  
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13 are however some differences between these two PROMs which are conducted during a semi-  
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15 structured interview. The ABILHAND consist of 23 exclusively bilateral ADL tasks that are  
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17 scored using a three-point ordinal scale while the MAM-36 consists of 36 unilateral and  
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19 bilateral ADL tasks which are scored using a four point ordinal scale (0-4). For both the  
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21 ABILHAND and MAM-36, a conversion table is available to obtain a Rasch-derived score,  
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23 which is regarded as superior to a summed score or calculated scores. The Disabilities of the  
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25 Arm, Shoulder, and Hand Scale (DASH)<sup>7</sup> and the Motor Activity Log (MAL)<sup>8</sup> are less  
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27 frequently used PROMs in MS and make use of summed or calculated total score. The DASH  
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29 measures the symptoms of upper limb dysfunction and the ability to perform unilateral and  
30  
31 bilateral activities by asking the patient to rate 30 tasks related to daily life using a five-point  
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33 ordinal scale reflecting the ease or difficulty perceived while performing the task. The MAL  
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35 measures during a semi-structured interview how much (amount of use scored from 0 to 5)  
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37 and how well (quality of movement scored from 0 to 5) a patient uses their more-affected  
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39 upper limb relative to its pre-illness use across 30 common, primarily unilateral ADL. While  
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41 this is an attractive construct that relates to upper limb performance in daily life, it may be  
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43 difficult for MS patients to compare their current upper limb functioning with a situation ‘pre  
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45 illness’.

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52 Recently, the Arm function in Multiple Sclerosis Questionnaire (AMSQ)<sup>9</sup> has been  
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54 introduced, which is a new PROM that was specifically developed to measure upper limb  
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3 disability for MS patients while other PROMs were developed in other health conditions as  
4 stroke, rheumatoid arthritis, cerebral palsy besides MS. During the AMSQ, patients are asked  
5 to rate to what extent MS has limited their ability to perform 31 unilateral and bilateral daily  
6 life activities using a six-point ordinal scale. The AMSQ-short form that is introduced in the  
7 current issue, contains only 10 items and seems a promising assessment tool in research and  
8 clinical practice. While applying a MS-specific scale seems appealing, and may be widely  
9 applied similar to the now acknowledged MS Walking Scale-12 (MSWS-12), it limits  
10 comparison with historical data in MS and other pathologies.  
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20 Psychometric properties of these PROMs were investigated using Rasch measurement  
21 methods or standard methods (intraclass correlations, standard error of measurement). The  
22 ABILHAND<sup>10</sup>, MAM-36<sup>6</sup> and the AMSQ<sup>11</sup> appeared to be reliable and valid in MS, in  
23 contrast to the low psychometric properties that were found for the DASH<sup>12</sup> and the lack of  
24 data for the MAL. Responsiveness in relation with the longitudinal progression of the MS  
25 (deterioration) or with improvement after treatment of MS patients has not yet been  
26 investigated for any of these PROMs which makes it yet premature to include it as a primary  
27 outcome measure in clinical trials. Most of the PROMs are available in different languages  
28 but cross-cultural validity was rarely investigated. It is strongly advised to design studies that  
29 directly compare the sensitivity of the different PROMs across MS patients with different  
30 upper limb disability levels in different countries and in comparison with clinical capacity  
31 tests such as the NHPT. Besides, the comparative sensitivity of PROMs compared to capacity  
32 measures to detect progression in clinical trials in progressive MS is also required as it is  
33 recently been shown that the MSWS-12 is more sensitive than the capacity walking tests in  
34 the early MS stage (EDSS 1-3).<sup>13</sup>  
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52 In conclusion, it is highly recommend to include PROMs to measure upper limb  
53 disability in MS and there are currently methodologically sound PROMs available which can  
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3 be used in the research and clinical practice. Further research is however needed to investigate  
4 the psychometric properties, in particular responsiveness, in the total MS population and  
5 subgroups of different upper limb disability levels.  
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