

# Long-term prognostic counselling in people with multiple sclerosis using an online analytical processing tool

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## Abstract

**Background:** Prognostic counselling is a sensitive issue in medicine and especially so in MS due to the highly heterogeneous disease course. However, people with MS (pwMS) seek prognostic information. The web-based ‘Evidence-Based Decision Support Tool in Multiple Sclerosis’ (EBDiMS) uses data of 717 patients from the London/Ontario cohort to calculate personalized long-term prognostic information.

**Objective:** The aim of this study was to investigate the feasibility and effect of long-term prognostic counselling in pwMS using EBDiMS.

**Methods:** Ninety consecutive pwMS were provided with personalized estimations of expected time to reach Expanded Disability Status Scale (EDSS) scores of 6 and 8 and time to conversion to secondary-progressive MS. Participants gave estimates on their own putative prognosis and rated the tool’s acceptability on six-step Likert-type scales.

**Results:** Participants rated EBDiMS as highly understandable, interesting and relevant for patient–physician encounters, coping and therapy decisions. Although it provoked a certain degree of worry in some participants, 95% would recommend using the tool. Participants’ own prognosis estimates did not change significantly following EBDiMS.

**Conclusion:** Long-term prognostic counselling using an online tool has been shown to be feasible in a clinical setting. EBDiMS provides pwMS with relevant, easy-to-understand, long-term prognostic information without causing relevant anxiety.

**Keywords:** Multiple sclerosis, long-term prognosis, prognostic counselling, risk communication, treatment decisions, online analytical processing tools

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## Introduction

Multiple sclerosis (MS) is a chronic inflammatory and degenerative disease of the central nervous system. The variability in disease progression makes estimation of prognosis challenging. While MS is benign in up to 30% of cases, it can also rapidly lead to disability.<sup>1–3</sup> A recent UK nationwide study with 3175 people with MS (pwMS) identified a frequently unmet need for prognostic information: 76% stated to seek information on their long-term prognosis and 53% had never discussed this topic with their physician. Nearly half of the participants (48%) even stated to have ‘no idea’ of their long-term prognosis.<sup>4</sup> A study conducted in Argentina in 2019 showed similar findings.<sup>5</sup> Physicians seem to refrain from openly communicating a possible prognosis, perhaps fearing

a ‘nocebo effect’ caused by providing unfavourable information.<sup>6</sup> This theory of ‘self-fulfilling prophecy’ ignores the patients’ right for prognostic information and to our knowledge is not built on substantial evidence.<sup>4,6,7</sup> Although not rigorously studied in neurological patients, there is evidence from oncology that prognostic counselling might lead to increased rates of patient satisfaction and decreased rates of depression without increasing anxiety.<sup>6</sup>

Providing individualized prognosis estimates to pwMS may be a way to promote adjustment to the disease and to facilitate treatment decisions. This is especially relevant as prevalence, phenomenology and prognosis of MS seem to substantially change with an increasing prevalence of a milder disease

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course.<sup>2,3,8</sup> Being confronted with an increasingly complex landscape of MS immunotherapies, a valid appraisal of one's individual prognosis together with an estimate of how disease-modifying drugs (DMDs) might alter it should become a *sine qua non* for balanced shared decision-making (SDM) on treatment.

Online analytical processing (OLAP) tools might be a way to provide individualized prognostic information. Based on patient characteristics, OLAP tools predict individual disease trajectories using data from large longitudinal patient cohorts. In a previous study, such a tool providing short-term prognostic information was shown to be understandable and not threatening, but of moderate relevance and interest for pwMS.<sup>9</sup> In 2013, Galea et al. reported on the 'Evidence-Based Decision Support Tool in MS' (EBDiMS), which, using a matching algorithm, provides an estimation of the individualized long-term prognosis (up to 30 years) based on the data of the London/Ontario cohort gathered from 1972 to 2000. In a survey comparing prognosis estimates of 17 neurologists specialized in MS with EBDiMS' estimates, both demonstrated a good and comparable accuracy when predicting the trajectory of real-life patient cases.<sup>10</sup>

This cross-sectional study aimed to assess the feasibility (i.e. understandability and acceptability), the safety and the perceived helpfulness of EBDiMS for long-term prognostic counselling for pwMS using a mixed-methods approach focusing on the patient perspective. We also conducted group comparisons (e.g. between different disease forms, levels of MS-related disability and levels of anxiety/depression) on the participants' own prognostic estimates, compared them to the tool and investigated if prognostic counselling leads to changes in pwMS' risk estimates.

## Methods

### *Study design*

In this cross-sectional study with short-term follow-up that was carried out in the MS day clinic of the University Medical Center Hamburg-Eppendorf, Germany, between October 2018 and March 2019, 90 pwMS were provided with personalized prognostic estimates of time to reach Expanded Disability Status Scale (EDSS) scores of 6 and 8, and, if applicable, conversion to secondary-progressive MS (SPMS). PwMS could participate in the study if they were 18 years and older and had clinically definite MS with EDSS < 6. Anxiety disorders, severe depression or cognitive dysfunction (based on clinical judgement) were exclusion criteria. The project was approved by

the Ethics Committee of the Hamburg Chamber of Physicians (PV6071).

After information about the study and written informed consent, eligible participants completed the pre-EBDiMS questionnaire, which asked for demographic and clinical data, and their own risk estimates regarding future disease progression. Then, they were led through the EBDiMS tool by a researcher. Prognosis estimation, referring to the historical London/Ontario cohort data as some kind of 'worst case natural history' scenario, was explained in a standardized way. After using the tool, participants completed the post-EBDiMS questionnaire which asked for another estimate of their future progression risk, and their perception of the tool.

Follow-up was performed approximately 14 days afterwards via short telephone interviews (5 to 10 minutes) to re-assess the psychological acceptability (degree of worry) in the medium term and to determine if EBDiMS had a persisting and relevant impact on the participants. Therefore, the participants were asked whether (and how frequently) they thought about the study again and if they had discussed the topic with other people (e.g. their significant others, friends or relatives). We also asked the participants if they felt the need to search other sources for further information on MS long-term prognosis.

### *Database for prognosis calculations*

EBDiMS is an OLAP tool for the individualized prognosis prediction of short- and long-term prognosis in MS. It has been developed by researchers from the Sylvia Lawry Centre for MS Research (SLCMSR) using the placebo arms of randomized controlled trials, observational studies and natural history cohorts comprising > 100,000 patient-years of data. In an external validation of the short-term tool usability and safety were confirmed.<sup>9,11</sup>

To estimate long-term prognosis, only data from one of the best-described patient cohorts, the London/Ontario cohort, were used.<sup>12</sup> Of 717 pwMS whose data were included in the tool's algorithm, 569 pwMS had a mean follow-up of 24 years and the other 148 pwMS who passed away during the study had a mean follow-up of 23 years.<sup>10</sup> To estimate individual prognosis, EBDiMS identifies pwMS from the database that are similar to the study participant with respect to gender, age at first symptoms, number of relapses in the first 2 years and MS disease course. The tool then generates an individualized prognosis estimate of the expected time to EDSS 6, EDSS 8 and conversion to

SPMS in years, which is displayed on screen. EBDiMS also displays a plot showing the average disease trajectory of the subjects chosen by the algorithm over a course of 30 years. The prognostic estimates in years refer to the median, that is, the 50th percentile.<sup>10</sup>

### Questionnaires

The initial versions of the two questionnaire sets (pre- and post-EBDiMS) were designed based on the previous work,<sup>9,13–15</sup> relevant literature<sup>16</sup> and the input of several researchers with different scientific backgrounds. In total, the participants answered 66 questions (41 pre-EBDiMS and 25 post-EBDiMS). The pre-EBDiMS questionnaire consisted of the following parts:

- (a) Hospital Anxiety and Depression Scale (HADS);<sup>17,18</sup>
- (b) Demographic and clinical data;
- (c) Patient Determined Disease Steps (PDDS) scale;<sup>19</sup>
- (d) Participants' estimates on their anticipated increase in MS-related disability over the next 5, 10 and 20 years (five-step Likert-type scales);
- (e) Participants' rating on the threat of wheelchair dependency on a visual analogue scale (range: 0–10);
- (f) Participants' expectation if (and in how many years) they expect to reach the disability milestones EDSS 6, EDSS 8 and (for pwRRMS) conversion to SPMS (with and without DMDs).

The post-EBDiMS questionnaire contained the following parts:

- (g) Re-assessment of the participants' risk estimates to evaluate EBDiMS' effect on these estimates: repetition of sections (d) and (f);
- (h) Participants' personal opinion on using the tool (e.g. if they would decide to use it again);
- (i) Participants' perception of the tool with respect to comprehensibility, familiarity with the information, interest, relevance, recommendation and emotional threat (six-step Likert-type scales ranging from 'not at all' to 'absolutely').

The questionnaires' feasibility was tested in five cognitive interviews, in which the think-aloud technique

was used, that is, participants went through the questionnaires verbalizing their thoughts.<sup>20</sup> Interviews were recorded and transcribed. To identify problems regarding wording ambiguity, comprehensibility and feasibility, analytical methods previously described by McCorry *et al.*<sup>21</sup> were employed. A coding framework was generated from any difficulties expressed by the participants, and inconsistencies between written and verbal responses.<sup>21</sup> Taking this framework into consideration, questionnaires were refined.

### Data analysis

SPSS (version 23.0) was used for the statistical analyses; *p*-values less than 0.05 were considered significant. Descriptive statistics were obtained on demographic data and perception of the prognostic information given by the tool. Paired-samples *t*-test or McNemar's test was used to assess whether pre- and post-EBDiMS risk estimations differed significantly.

Group comparisons using non-paired *t*-test were employed to determine the effect of MS disease course, PDDS and HADS scores, as well as disease duration on participants' estimates. To evaluate whether participants' estimates on expected progression over the next 5, 10 and 20 years (five-step Likert-type scales) were influenced by disease covariates or sociodemographic factors, several group comparisons using paired-samples *t*-tests were performed. In the interest of clarity and because pre- and post-EBDiMS values of the participants' risk estimates assessed on the aforementioned Likert-type scales did not significantly differ, only pre-EBDiMS values will be reported in this paper.

An analysis of covariance (ANCOVA) using stepwise exclusion was performed to investigate the impact of sociodemographic factors and disease covariates on participants' estimates in years. The following covariates were included in the models: age, disease duration, PDDS, perceived progression during the last 12 months (five-step Likert-type scale) and HADS scores. MS disease course was included as a fixed factor.

## Results

### Demographics

Of 126 pwMS who were asked to participate, 36 declined. The most frequent reason for declining participation in the study was anxiety relating to the prognostic estimate. Of the final 90 pwMS (72% relapsing-remitting MS (RRMS), 12% secondary-progressive MS

(SPMS) and 16% primary-progressive MS (PPMS)), 50% were female (see Table 1). Mean age was 43.8 (SD = 9.5) years, mean disease duration was 9 (SD = 6.9) years and mean EDSS was 2.5 (SD = 1.1).

All participants stated to be interested in receiving more information on their presumed prognosis using EBDiMS. As shown in Figure 1, 65% reported they had never received prognostic counselling before, although 60% would have preferred it; 54% would have liked earlier access to EBDiMS; 31%

would have wanted to use EBDiMS within the first weeks after diagnosis; and 11% stated they would have wanted to use EBDiMS, at the earliest, 10 years after diagnosis. The majority of the 45 participants receiving DMDs believed the effect of their medication on long-term prognosis to be 'huge' or 'very huge'.

Mean score for anxiety (HADS-A) was 5.8 out of 21 (SD = 3.5), and mean score for depression (HADS-D) was 4.8 out of 21 (SD = 4.0) (Table 1). Participants were asked to rate wheelchair dependency on a scale from 'not at all frightening' to 'worst thing which could happen', and they reached an average score of 7.1 out of 10 points.

**Table 1.** Demographic data.

Female (%)	50
RRMS/SPMS/PPMS (%)	72/12/16
On immunotherapy (%)	50
Mean age (years)	43.8 (9.5)
Mean disease duration (years)	9 (6.9)
Mean EDSS	2.5 (1.1)
HADS-D normal/borderline/abnormal (%)	74/14/11 <sup>a</sup>
HADS-A normal/borderline/abnormal (%)	79/11/10
Mean HADS-D subscore	4.8 (4.0)
Mean HADS-A subscore	5.8 (3.5)

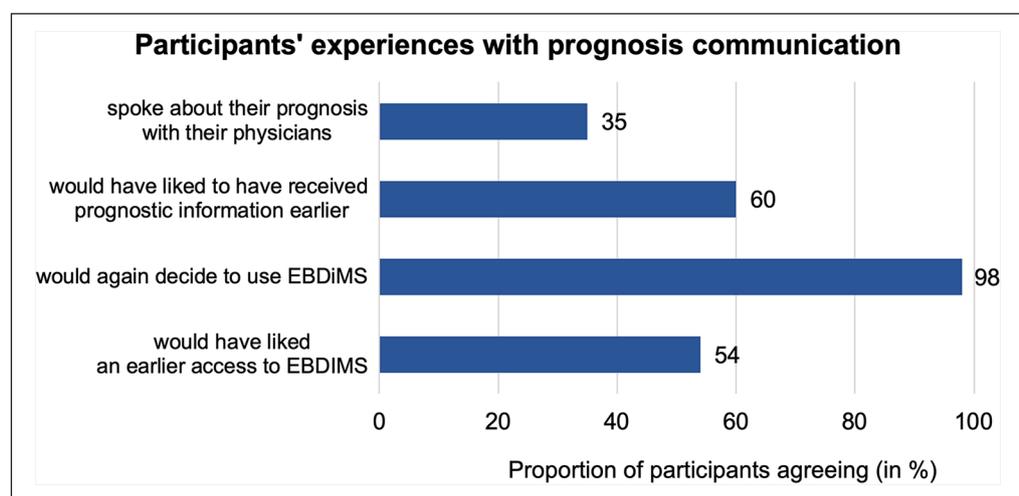
This table shows the demographic data of the 90 participants. Data are percentages or mean values  $\pm$  SD in brackets.

<sup>a</sup>Does not add up to 100% due to rounding.

SD: standard deviation; RRMS: relapsing-remitting multiple sclerosis; SPMS: secondary-progressive multiple sclerosis; PPMS: primary-progressive multiple sclerosis; EDSS: Expanded Disability Status Scale; HADS-A: Hospital Anxiety and Depression Scale (Anxiety); HADS-D: Hospital Anxiety and Depression Scale (Depression).

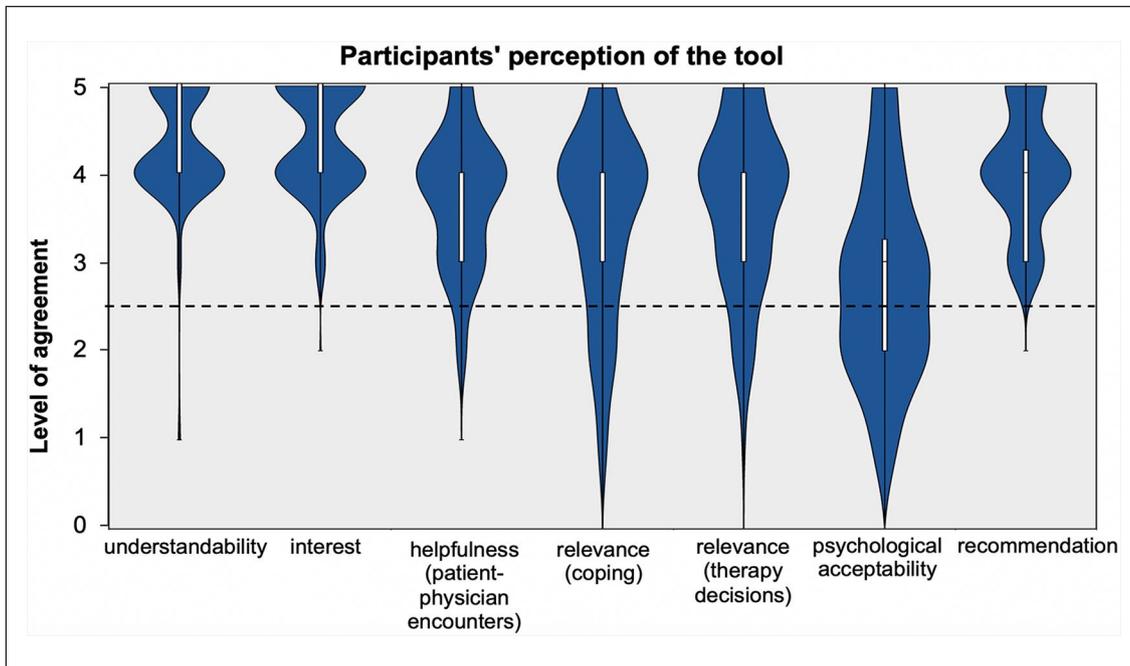
### Perception of the OLAP tool

Overall, conveying personalized prognostic information using EBDiMS was highly acceptable for pwMS (Figure 1). On six-step Likert-type scales (range: 0–5, from 'not at all' to 'absolutely'), EBDiMS was rated as very understandable and very interesting as well as relevant for patient–physician encounters, coping with the disease and therapy decisions. Overall, EBDiMS was psychologically acceptable and did not cause significant anxiety. However, 43% of the participants claimed that EBDiMS led at least to a certain degree of worry (i.e. less than 3 out of 5 points on the Likert-type scale assessing psychological acceptability). Two participants who developed an acute stress reaction following EBDiMS had to be coached by a psychologist.



**Figure 1.** Participants' experiences with prognosis discussion.

The diagram shows the experiences of 90 participating pwMS relating to prognosis discussion. Data are shown as percentages of participants answering 'yes'. pwMS: person with multiple sclerosis; EBDiMS: Evidence-Based Decision Support in Multiple Sclerosis.



**Figure 2.** Participants' perception of EBDiMS.

The boxplots represent the participants' rating on six-step Likert-type scales (range: 0–5), with the violin plot outlining the distribution of the answers. The width of the coloured area illustrates the proportion of data allocated there. The extreme poles of the Likert-type scale were labelled high and low, to assess understanding (no understanding vs complete understanding), interest (not interesting vs highly interesting), relevance (not relevant vs highly relevant), psychological acceptability (threatening vs reassuring) and degree of recommendation (not recommendable vs highly recommendable). Data are shown as median and quartiles, with whiskers reaching up to 1.5 times the interquartile range. The plot was created with BioVinci software (BioTuring Inc., San Diego, USA).

**Table 2.** Participants' prognostic estimates (yes/no answers).

Item		Pre-EBDiMS	Post-EBDiMS	<i>p</i> -value
Expect to reach EDSS 6	Without immunotherapy	70 (77.8%)	79 (87.8%)	0.004
	With immunotherapy	47 (52.2%)	63 (71.1%)	<0.001
Expect to reach EDSS 8	Without immunotherapy	36 (40.0%)	45 (60.0%)	0.064
	With immunotherapy	22 (24.4%)	26 (28.9%)	0.424

This table shows the prognostic estimates (yes/no answers) of 90 participating pwMS. pwMS: person with multiple sclerosis; EBDiMS: Evidence-Based Decision Support in Multiple Sclerosis; EDSS: Expanded Disability Status Scale.

Despite this, 86 out of 90 (96%) of the participants would recommend using EBDiMS, and 88 out of 90 (98%) did not regret using the tool (Figure 2).

### Prognostic estimates

Following exposure to EBDiMS, the number of participants expecting to ever reach EDSS 6 if they did not take DMDs increased significantly from 78% to 88% ( $p=0.004$ ) and if they did take DMDs from 52% to 71%. For EDSS 8, numbers increased non-significantly from 40% to 50% without DMDs and from 24% to 29% with DMDs (Table 2).

Mean prognostic estimates calculated by EBDiMS were 17.09 (SD = 4.54) years to reach EDSS 6 and 25.64 (SD = 5.08) years to reach EDSS 8. For pwRRMS, estimated time until SPMS conversion calculated by EBDiMS was 16.2 (SD = 3.3) years. Before and after using the tool, those participants expecting to ever reach EDSS 6, EDSS 8 or to convert to SPMS estimated their future disease progression *with* and *without* DMDs, that is, they were asked in how many years they expected to reach these disability milestones if they were or were not taking DMDs. All estimates were significantly more favourable than the ones calculated by the tool

**Table 3.** Participants' prognostic estimates (years).

		Estimation by participants' pre-EBDiMS	Estimation by participants' post-EBDiMS	<i>p</i> -value Pre- vs post-EBDiMS	Estimation by EBDiMS	<i>p</i> -value Participants' pre-EBDiMS vs EBDiMS	<i>p</i> -value Participants' post-EBDiMS vs EBDiMS
Expected time to EDSS 6 (years)	Without DMDs	20.5 (9.67)	21.7 (8.6)	0.269	17.09 (4.54)	0.003	<0.001
	With DMDs	24.9 (11.9)	25.9 (10.3)	0.445		<0.001	<0.001
Expected time to EDSS 8 (years)	Without DMDs	29.5 (11.7)	29.1 (10.2)	0.090	25.64 (5.08)	0.072	0.038
	With DMDs	34.8 (11.7)	33.1 (9.5)	0.411		<0.001	<0.001

This table shows the prognostic estimates of 90 participating pwMS in years (with and without DMDs) and the tool's estimates. Data are shown as mean values  $\pm$  SD in brackets. *p*-values are based on paired-samples *t*-test. pwMS: person with multiple sclerosis; EBDiMS: Evidence-Based Decision Support in Multiple Sclerosis; EDSS: Expanded Disability Status Scale; DMD: disease-modifying drug; SD: standard deviation.

(except for time to EDSS 8 without immunotherapy pre-EBDiMS with  $p=0.072$ ). Even after revealing the more pessimistic estimates of the tool, the participants' ones did not change significantly (Table 3; Supplemental Table S1).

Participants also estimated how much they expected their MS-related disability to increase over the next 5, 10 and 20 years using five-step Likert-type scales (ranging from 'not at all' to 'very severe'). These estimates, again, did not change significantly after receiving personalized prognostic information (all  $p > 0.05$ ; Supplemental Table S2).

#### Group comparisons

When comparing participants with PDDS  $< 3$  versus PDDS  $\geq 3$ , estimates concerning MS-related disability progression (five-step Likert-type scales, range: 0–4) were significantly different between these two groups: 0.94 versus 1.59 for 5 years; 1.31 versus 1.87 for 10 years; 1.65 versus 2.15 for 20 years (all  $p < 0.05$ ). This indicates that more severely affected participants tended to have a more negative outlook on their future disease progression (Supplemental Table S3). Furthermore, participants with PPMS/SPMS had a significantly more pessimistic view of their future than those with RRMS ( $p < 0.05$  for 5, 10 and 20 years when comparing PPMS/SPMS vs RRMS).

Depressed participants (HADS-D  $\geq 8$  points) were more pessimistic than participants with HADS-D  $< 8$  points when estimating their future disease progression (all  $p < 0.05$  when comparing HADS-D  $\geq 8$  vs HADS-D  $< 8$ ). In this study population, there was also no significant difference between anxious (HADS-A  $\geq 8$  points) and non-anxious participants

(HADS-A  $< 8$ ). Disease duration did not significantly influence participants' estimates either (Supplemental Table S3). When comparing anxious (HADS-A  $\geq 8$ ) versus non-anxious (HADS-A  $< 8$ ) participants, psychological acceptability was significantly lower in anxious participants (2.26 vs 2.93;  $p = 0.03$ ) (Supplemental Table S5).

#### ANCOVA

After stepwise exclusion of non-significant variables, the final ANCOVAs consisted of two to four variables. Across all models, between 25.0% and 62.4% of the variance could be explained. The variables with the greatest predictive value were age, PDDS, disease duration and perceived progression during the last 12 months. *F*- and *p*-values, as well as  $\eta_p^2$  and  $R^2$ , are reported in Supplemental Table S4.

#### Follow-up

Follow-up was performed via telephone approximately 14 days after exposure to EBDiMS. The majority (69%) of the 64 participants, that could be reached, stated they had thought about the study occasionally to frequently. Ninety-one percent had discussed the study with other people: 61% of them with significant others, 44% with relatives, 47% with friends and 25% with physicians. Only 20% stated to have searched other sources for further information on MS long-term prognosis. Degree of worry (mean = 3.12 (SD = 1.16); five-step Likert-type scale) was not significantly different from immediately after using EBDiMS ( $p = 0.398$ ).

#### Discussion

Discussion of prognosis in medicine is a sensitive issue – especially so in MS due to the heterogeneous

disease course. This cross-sectional study investigated the use of an OLAP tool providing personalized long-term prognosis estimates to 90 pwMS in order to clarify its usefulness for participants as well as its impact on their risk perceptions.

One of the main findings was that 64% of pwMS participating in this study reported never having received prognostic counselling before, although 60% would have wanted it. This is in line with findings from other recent surveys,<sup>4,5</sup> indicating a strong desire for long-term prognostic information that could possibly have helped pwMS to adjust to the disease and make complex treatment decisions.

Importantly, this study shows that prognostic counselling using the tool is feasible in a clinical setting. Participants rated EBDiMS as very understandable, interesting, as well as relevant for coping, patient–physician encounters and treatment decisions. As shown in other studies, participants stated to prefer receiving prognostic information with the guidance of a doctor.<sup>4</sup> In general, EBDiMS was psychologically acceptable and did not raise any serious safety concerns in this group of participants without known or evident anxiety disorders. However, as EBDiMS led to a certain degree of worry in 43% of pwMS and induced acute stress reactions in two participants, this needs further study. Both of these participants had a low disease-related knowledge as well as coping problems, suggesting that this response could be predicted by screening and potentially prevented by improving their disease-related knowledge prior to EBDiMS tool exposure. However, as we excluded pwMS with diagnosed psychiatric illnesses, our results cannot be assumed to be generalizable to pwMS with these comorbidities.

In this study, as expected, more severely affected participants had a more negative outlook on their future disease progression. PDDS, disease duration, perceived progression during the last 12 months and age were identified as the variables with the strongest influence on participants' prognostic estimates. Interestingly, participants' prognostic estimates were more optimistic compared to those calculated by EBDiMS and did not change after using the tool. This is in line with the fact that more than half of the participants stated they did not expect EBDiMS' prognostic estimates to apply to them. Participants' estimates might be more optimistic due to taking DMDs, coping strategies or even considering that MS nowadays is different from a Canadian cohort up to 50 years ago. This finding reflects the complex interplay of processing group estimates with ideas about one's own prognosis. Here it has been demonstrated

that perception of one's own personal prognosis is better, when compared to the prognosis of individuals from a comparable group which can be considered as a major life-coping mechanism.<sup>22</sup>

OLAP tools have a long history in medicine. The first attempts at an automatic evaluation of electrocardiograms with the help of computer programmes were made in the late 1950s.<sup>23</sup> Today, OLAP tools are applied in several specialties such as obstetrics (e.g. interpretation of cardiotocograms)<sup>24</sup> and oncology (e.g. survival prediction).<sup>25</sup> While these tools' accuracy and validity has frequently been studied<sup>26,27</sup> and compared against each other,<sup>28</sup> the patients' perspective has received less attention, including the patients' perception of these tools, their own estimates or the tools' influence on these estimates.

Prognosis forecasting tools are still in their infancy in neurology. Since EBDiMS is based on one of the best-described MS natural history cohorts, the London/Ontario cohort, it employs data of untreated patients that has been gathered between 1972 and 2000.<sup>12</sup> However, the prognosis of pwMS diagnosed today seems to be different<sup>29,30</sup> due to several reasons, including more frequent diagnosis with a milder course based on new diagnostic criteria, the so-called Will Rogers phenomenon,<sup>31</sup> ascertainment bias (loss to follow-up), better general medical management and possibly also DMDs.

Taken together, prognostic counselling using EBDiMS has been shown here to be feasible, helpful and highly appreciated by pwMS, as well as safe in this study population without diagnosed or evident psychiatric illnesses. This encourages the use of state-of-the-art predictive tools. Further research is needed to develop tools capable of providing better personalized long-term prognostic estimates that will preferably include information on the treatment effects (and risks) of DMDs. These tools could integrate information from larger registries, MRI findings and/or other biomarkers in their matching algorithms to provide more accurate and detailed estimates on long-term prognosis, possibly leading to a more positive perception of the presented information. Such estimates are not only needed when making complex treatment decisions but will also help pwMS accept the uncertainties of their disease and thereby give them space for the hope of a more favourable course.

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### Supplemental Material

Supplemental material for this article is available online.

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