



## Original article

# Diagnosis concealment is prevalent in MS, and associated with diagnosis experience

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## ABSTRACT

**Background:** Receiving a diagnosis of multiple sclerosis (MS) can be stressful; later, patients may conceal their diagnosis. Here, we aimed to (1) assess prevalence of disclosure and concealment behaviors, and (2) explore whether diagnosis experience is associated with later concealment and if MS provider engagement on this topic modifies concealment.

**Methods:** In a survey-based study, MS patients completed DISCO-MS assessing disclosure and concealment and responded to questions about diagnosis experience and practitioner attention to disclosure. Frequency analysis and Pearson's correlations were used in exploratory analyses.

**Results:** 428 adults with MS participated. 49% ( $N = 201$ ) conceal their diagnosis. Higher education [ $t(405) = 3.66, p < 0.001$ ], younger age ( $r = -0.15, p = 0.002$ ), and shorter disease duration ( $r = -0.18, p = 0.010$ ) were associated with higher concealment. 39% ( $N = 159$ ) anticipate negative consequences of disclosure. Individuals reporting positive diagnosis experience (26%,  $N = 102$ ) were less likely to conceal later in disease course compared to those with negative experience (34%,  $N = 136$ ) [ $t(233) = 2.483, p = 0.014$ ]. Patients whose MS providers discussed disclosure (23%,  $N = 73$ ) anticipated less negative consequences of disclosure [ $t(323) = 2.475, p = 0.014$ ].

**Conclusions:** Diagnosis concealment is common in MS. Favorable diagnosis experience and provider attention to the topic of disclosure throughout the MS disease course may influence diagnosis concealment.

## 1. Introduction

Many people with chronic medical conditions make careful decisions about when and whether to disclose their diagnosis. Multiple sclerosis (MS) is an unpredictable neurological disease with onset in early adulthood. Many of the most disabling symptoms of MS are invisible (e.g., fatigue, pain, depression, anxiety, cognitive impairment (Krupp et al., 1988; O'Connor et al., 2008; Marrie et al., 2017; Sumowski et al., 2018)); thus, patients are often faced with decisions about sharing their MS diagnosis. Such decisions can be stressful, as patients navigate real and perceived consequences of disclosure (Cook et al., 2016; Spencer

et al., 2019) that vary depending on context, content, and extent of disclosure. MS patients describe making almost constant calibrations regarding disclosure decisions whereby even responding to a simple 'how are you?' becomes a source of stress (Leavitt and Kever, 2022).

The DISCO-MS was developed to assess frequency of concealment and beliefs about consequences of disclosure in MS. please replace with (Kever and Leavitt, 2022); Kever et al., 2022) A preliminary validation study of the instrument found that approximately 42% of patients conceal their diagnosis (please replace with (Kever and Leavitt, 2022). Higher concealment was associated with younger age, shorter disease duration, lower physical disability, and higher depression and anxiety

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(Please replace with (Kever and Leavitt, 2022)). Nearly 50% of individuals believed that disclosing their diagnosis could have negative consequences in professional and personal settings. Individuals who anticipated negative consequences of disclosure were lonelier and had lower social support and self-efficacy (Kever et al., 2022), outcomes linked to poor health outcomes (Braveman and Gottlieb, 2014; Thoolen et al., 2008).

The present study had two aims: first, to replicate the findings of the initial (smaller) DISCO-MS validation study in a larger sample of convenience in order to determine the prevalence of diagnosis concealment in patients with MS and demographic or clinical factors associated with concealment. Second, we aimed to explore whether patient experience of being diagnosed with MS is related to subsequent concealment behaviors and disclosure beliefs. Receiving an MS diagnosis can be stressful (Topcu et al., 2022). Many describe the experience as traumatic (Barskova and Oesterreich, 2009; Chalfant et al., 2004), with some patients acknowledging that they revisit the experience each year (i.e., anniversary effect). Our understanding of whether a patient's diagnosis experience informs psychosocial adjustment and impacts subsequent disability and quality of life in MS is incomplete. Here, we explore associations between diagnosis experience and how patients navigate their disease course including choices about disclosure and concealment. Finally, we asked patients whether their MS provider addresses the topic of disclosure, and evaluated whether provider attention to the topic is associated with patients' disclosure beliefs and concealment behaviors.

## 2. Methods

These data are part of a larger patient survey study aiming to understand patient experience surrounding MS diagnosis completed in collaboration with Accelerated Cure Project and performed within the participatory research network (iConquerMS.org). A survey was developed to assess: the experience of receiving a diagnosis of MS, MS provider communication and shared decision making at the time of and immediately after diagnosis, and whether patients subsequently share their diagnosis of MS.

The survey instrument (see supplemental materials) included: (1) a patient self-report instrument previously utilized to survey patients receiving a diagnosis of motor neuron disease (Aoun et al., 2016), now modified for MS, (2) a previously validated patient self-report instrument that assesses satisfaction with communication of a diagnosis of MS (Solari et al., 2010), the Comunicazione medico-paziente nella Sclerosi Multipla (COSM-R), translated from Italian (note that additional data regarding COSM-R responses will be subsequently reported elsewhere), (3) a previously validated patient self-report instrument to measure behaviors and beliefs about diagnosis disclosure and concealment in individuals with MS - Diagnosis Disclosure and Concealment in MS Scale (DISCO-MS please replace with (Kever and Leavitt, 2022)), (4) three additional non-validated questions pertaining to diagnosis anniversary effect and provider queries related to diagnosis disclosure, (5) demographic questions, and (6) PDDS (Patient Determined Disease Steps) data collected as part of participation in the other iConquerMS studies were shared by the Accelerated Cure Project for participants who completed the study survey instrument. The PDDS is a self-report measure of disability status validated for use in MS (Learmonth et al., 2013). PDDS data were only included if the measure had been completed within a year prior to the survey start date. If more than one PDDS was completed by a study participant within this 12-month timeframe, the most recent completed PDDS was included for the study.

An initial draft of the survey instrument was reviewed by the iConquerMS Research Committee comprised of people with research and medical expertise, including scientists and medical professionals, more than half of whom are also people diagnosed with MS. The committee provided feedback to improve clarity, and survey questions were modified based on these suggestions. No modifications were made to previously validated instruments (COSM-R and DISCO-MS). The

committee gave approval to conduct the study within the iConquerMS network.

The final survey was created as an online instrument by the Accelerated Cure Project on the iConquerMS Drupal-based data collection platform and made available to participants of iConquerMS for six weeks spanning November 12, 2021, through December 22, 2021. Periodic reminders were sent to iConquerMS participants to encourage completion of the survey. Study participation included the possibility (by lottery at study completion) of receiving an incentive in the form of a gift card. This study therefore utilized a convenience sample, and no formal power analysis was conducted.

The data reported herein focus on DISCO-MS responses, and potential associations with questions surrounding diagnosis experience. As mentioned, additional descriptive survey result data (particularly COSM-R responses), will be reported in future publications.

### 2.1. Analytic approach

Frequency analysis was used to evaluate response rates for DISCO-MS parts I and II, and for each subscale within the DISCO-MS. Associations of DISCO-MS subscales with demographics, clinical characteristics, and additional questions about diagnosis experience and provider attention to the topic of disclosure were evaluated using Pearson's correlations. Associations with non-normally distributed variables were assessed using Spearman correlations. One-way analysis of variance (ANOVA) tests were performed to assess between-group differences for binary choice items; in some cases, results of follow-up t-tests are displayed. Although DISCO-MS is a validated instrument, evaluating an association between its scoring and diagnosis experience is exploratory and we do not correct for multiple comparisons in reported p-values. Therefore, statistical significance is interpreted with caution and future studies will be required to validate the findings of the present study.

The study was approved by the University of Vermont Institutional Review Board.

## 3. Results

### 3.1. Participants

A total of 428 adults with MS participated in the study. The sample included participants from 18 different countries, with 88.1% from 42 states within the US. Participants were predominantly female (80%), age ranged from 21–81 years (mean 56.2 years). Most participants identified as white (94.3%,  $N = 380$ ), 2.7% ( $N = 11$ ) as Black, 0.7% ( $N = 3$ ) Asian, and 2.2% ( $N = 9$ ) as other. 87.6% ( $N = 355$ ) of participants were college educated (associate degree or higher). Regarding employment status, 40.1% ( $N = 162$ ) were employed, 4.7% ( $N = 19$ ) unemployed, 16.3% ( $N = 66$ ) retired, and 33.9% ( $N = 137$ ) reported disabled work status. Average years since MS diagnosis was 15.8 (range=1–64). Disease phenotype at onset was reported as relapsing-remitting MS by 80.6% ( $N = 340$ ) and median score on the PDDS from 356 study participants who completed it within the last year was 3.0, i.e., moderate disability with onset of gait impairment. Table 1 displays detailed demographic and clinical characteristics.

### 3.2. DISCO-MS survey

Of the 428 participants, 410 (96%) completed the DISCO-MS (Part I,  $n = 410$ ; Part II,  $n = 406$ ). For summary of results, please see Fig. 1.

*Part I: Diagnosis concealment behaviors:* 49% of participants reported that they sometimes, often, or always conceal their MS diagnosis. More frequent diagnosis concealment was associated with younger age ( $r = -0.15$ ,  $p = 0.002$ ) and shorter disease duration ( $r = -0.18$ ,  $p = 0.010$ ), and lower disability status (PDDS,  $r = -0.20$ ,  $p < 0.001$ ). Concealment behavior was associated with education level, with college-educated participants reporting more concealment behavior [ $t(405) = 3.66$ ,  $p$

**Table 1**  
Demographics and clinical characteristics.

	(n = 428)
Age, mean (SD)	56.2 (12.3)
Female sex, N (%)	324 (80.2)
Country of residence, N (%)	
United States	357 (88.1)
Australia	1 (0.2)
Belgium	1 (0.2)
Canada	25 (6.2)
Ghana	1 (0.2)
Greece	1 (0.2)
Ireland	4 (1.0)
Israel	1 (0.2)
Luxembourg	1 (0.2)
New Zealand	1 (0.2)
Norway	1 (0.2)
Philippines	1 (0.2)
Serbia	1 (0.2)
Spain	3 (0.7)
Switzerland	1 (0.2)
Thailand	1 (0.2)
Ukraine	1 (0.2)
United Kingdom	3 (0.7)
Race N (%)	
White	380 (94.3)
Black	11 (2.7)
Asian	3 (0.7)
Other	9 (2.2)
Ethnicity N (%)	
Hispanic	15 (3.7)
Non-Hispanic	390 (96.3)
Education N (%)	
High school	18 (4.4)
Some College	30 (7.4)
Associate degree	36 (8.9)
Technical degree	8 (2.0)
Bachelor's degree	146 (36.0)
Master's degree	103 (25.4)
Doctoral degree	62 (15.3)
N/A	2 (0.6)
Employment N (%)	
Employed	162 (40.1)
Homemaker	10 (2.5)
Student	5 (1.2)
Unemployed	19 (4.7)
Disabled	137 (33.9)
Retired	66 (16.3)
N/A	5 (1.2)
Years since MS symptom onset, mean (SD)	24.8 (13.4)
Initial MS symptom N (%)	113 (26.4)
Vision	56 (13.1)
Dizziness	193 (45.1)
Sensory	143 (33.4)
Weakness	137 (32.0)
Other	340 (80.6)
Initial MS type diagnosed N (%)	28 (6.6)
RRMS	8 (1.9)
PPMS	33 (3.1)
SPMS	13 (7.8)
Other	15.8 (11.6)
Not sure	3.0 (4)
Years since diagnosis, mean (SD)	
PDDS, median (IQR)	

RRMS: relapsing-remitting MS; PPMS: primary progressive MS; SPMS: secondary progressive MS; PDDS: Patient Determined Disease Steps.

< 0.001]. Concealment behavior was not associated with age at diagnosis or sex. Association of concealment and race/ethnicity was not assessed due to homogeneity of the sample.

**Part II: Diagnosis disclosure beliefs.** With regard to anticipation of general negative consequences, 39% (N = 159) of participants reported that they agree or strongly agree that disclosing their diagnosis will

result in negative consequences. Younger current age ( $r = -0.18, p < 0.001$ ) and younger age at the time of diagnosis ( $r = -0.11, p = 0.026$ ), and worse disability (trend-level,  $r = 0.11, p = 0.05$ ) were associated with greater anticipation of negative consequences. No significant associations with any other clinical/demographic variables were observed. 71% (N = 286) of participants reported that they believed that disclosure would have positive consequences (note that the scale is designed such that anticipation of negative consequences does not preclude anticipation of positive consequences; many patients have expectations of both). Longer disease duration was related to greater anticipation of positive consequences of disclosure ( $r = 0.16, p = 0.023$ ); no associations with any other demographic or clinical variables were found. With regard to anticipated consequences for *personal relationships*, 35% (N = 140) of participants reported that they anticipated a negative impact of disclosure. Younger current age ( $r = -0.14, p = 0.023$ ), younger age at time of diagnosis (trend-level,  $r = -0.12, p = 0.049$ ), and worse disability ( $r = 0.31, p < 0.001$ ) were associated with greater anticipation of negative impact for personal relationships. With regard to anticipated consequences of disclosure in *professional relationships*, 43% (N = 175) of participants expected disclosure to have a negative impact. Younger current age ( $r = -0.14, p = 0.005$ ) and younger age at the time of diagnosis ( $r = -0.12, p = 0.016$ ) were associated with greater expected negative consequences of diagnosis disclosure. Anticipated consequences of disclosure on professional life were associated with education level, with college-educated participants reporting more negative impact [ $t(405) = 2.77, p = 0.006$ ].

**Diagnosis Experience.** Patients who reported feeling that they were given sufficient time to express their emotions at the time of diagnosis reported engaging in less concealment behavior [ $t(157) = 2.648, p = .011$ ], and expecting less overall [ $t(156) = 2.415, p = .017$ ], professional [ $t(156) = 2.326, p = .021$ ], and personal [ $t(156) = 3.180, p = .002$ ] negative consequences of disclosing their diagnosis compared to those who felt they were not given enough time. Similarly, patients who reported not having been provided with enough information at the time of diagnosis reported anticipating more overall [ $t(380) = 2.479, p = .014$ ], professional [ $t(380) = 3.219, p = .001$ ], and personal [ $t(380) = 2.198, p = .029$ ] negative consequences of disclosing compared to those who received enough information. When asked how they would describe their overall diagnosis experience, 32% (N = 136) of participants responded "negative" or "very negative", and 24% (N = 102) positive or very positive. Those who perceived their overall diagnosis experience as very positive engaged in significantly less concealment than those who perceived it as negative [ $t(113) = 3.242, p = .002$ ].

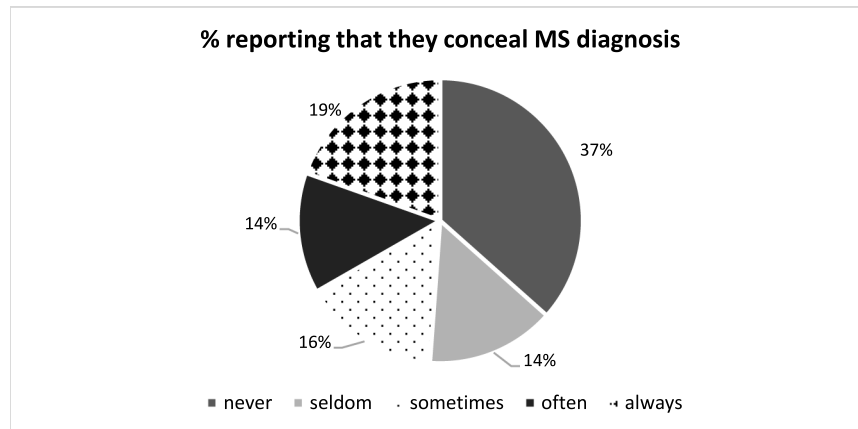
**Anniversary effect.** Patients who do versus those who do not experience anniversary effect did not report differences in concealment behaviors. Those who experience an anniversary effect reported anticipating more negative consequences of disclosure overall [ $t(197) = 3.050, p = .003$ ], and in professional [ $t(197) = 3.960, p < .001$ ], and personal [ $t(197) = 2.748, p = .007$ ] settings compared to those who do not experience an anniversary effect.

**MS provider communication regarding disclosure.** In response to the question "Have any of your MS providers ever asked you whether you share your MS diagnosis with others," 23% (N = 73) said yes, and 77% (N = 252) said no. There was no observed difference between these two groups in concealment behaviors. However, participants who reported having been asked about disclosure reported less anticipation of negative consequences of disclosure [ $t(323) = 2.475, p = .014$ ] and more anticipation of positive consequences [ $t(323) = 3.958, p < .001$ ] in professional contexts than those whose practitioners never discussed disclosure.

#### 4. Discussion

This study confirms prior preliminary data suggesting that diagnosis concealment is common in patients with MS (Keever and Leavitt, 2022). We found that almost half of the MS patients we surveyed reported

a.



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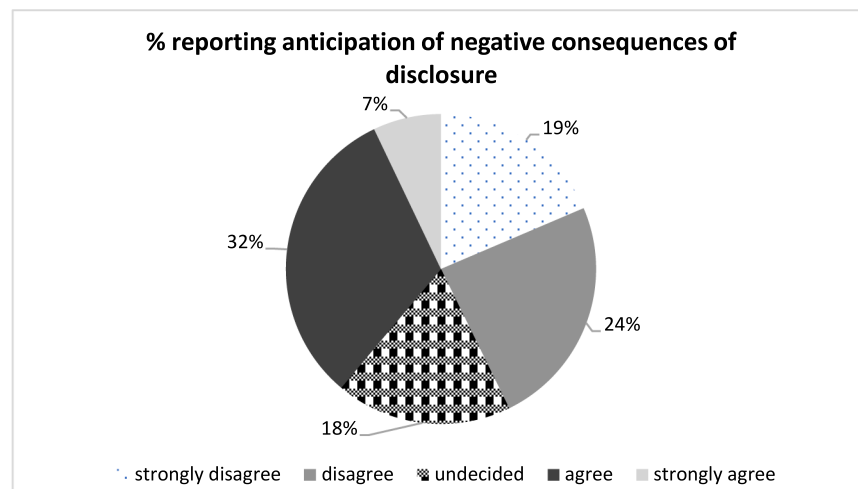


Fig. 1. should be "DISCO-MS responses.

concealing their diagnosis, and more than a third reported anticipating negative consequences of disclosure in personal and/or professional contexts. The study also provocatively suggests the possibility that a negative experience associated with receiving a diagnosis of MS subsequently influences behaviors, concerns, and expectations surrounding diagnosis disclosure and concealment. We also report for the first time that over three-quarters of MS patients have never been asked about disclosure and concealment by their MS practitioner, and that such conversations may influence these behaviors.

The present results confirm demographic and clinical characteristics associated with MS diagnosis concealment identified in our prior preliminary study (Kever and Leavitt, 2022). Higher diagnosis concealment was associated with younger age and shorter time since diagnosis. While reasons for this cannot be known directly from the present study, we speculate that patients who are able to conceal (i.e., have less visible disability) their MS are more inclined to do so. Indeed, we also found that diagnosis concealment was associated with lower scores on PDDS. Higher scores on this measure correspond to more visible MS-related disability (i.e., ambulation impairment).

Patients who had a negative experience of diagnosis were more likely

to conceal their diagnosis later in their disease course. Although further studies are needed to fully understand reasons for a negative diagnosis experience, this study indicated that being given sufficient time during the diagnosis experience was a key piece. Interestingly, we also found that patients who reported feeling they had been given inadequate time or information during their MS diagnosis reported more anticipation of negative consequences of disclosing their diagnosis in both personal and professional spheres. One possible interpretation for this finding is that the diagnosis experience was traumatic. Consistent with this interpretation is our finding that anniversary effect (Bornstein and Clayton, 1972), the extent to which MS patients reported thinking about their diagnosis annually, was also related with greater expectations of negative consequences of disclosure, suggesting that experiencing the MS diagnosis as traumatic is associated with whether people conceal their diagnosis later in their disease course. This is a potentially impactful consequence, given previous and current findings linking greater anticipation of negative consequences of disclosure to health risk factors such as higher loneliness, lower social support, and lower self-efficacy (Kever et al., 2022), as well as associations with higher depression and higher anxiety please replace with (Kever and Leavitt, 2022) A

traumatic diagnostic experience may set patients on a trajectory for poor health outcomes later in the disease course.

Our study has limitations. The racial/ethnic composition of our sample is homogeneous, precluding evaluation of differences in disclosure and concealment that may occur within underrepresented minorities, a topic that warrants consideration in future work. Although respondents were drawn from 18 different countries, the sample is predominantly from the United States. In addition, our sample disproportionately comprises highly educated participants, with over 76% holding a college degree or higher. Survey items about the diagnosis experience have not yet been validated in a formal measure, and their inclusion in the present study represents a preliminary, exploratory use of these items. There are two sources of potential sample bias that must be considered: referral bias: participants in this study were self-referred to a research network (iConquerMS) and may systematically differ from a general or clinic-based population; and second, our use of a sample of convenience, which precluded formal power analysis to determine sample size. Finally, the exploratory nature of this study limited the scope of our statistical analysis. We did not correct for multiple comparisons, and we did not adjust for potential confounders in our analysis of diagnosis experience. While age and disease duration may impact recall of the diagnosis experience, there is evidence showing that autobiographical memory for remote events increases with age (Gardner et al., 2015). While our results are broadly in agreement with those from previous work please add citation (Kever and Leavitt, 2022), future confirmatory studies with more diverse samples would bolster the robustness of our findings.

This study confirms that diagnosis concealment in MS is prevalent, and that further work to understand its full impact on patient quality of life is needed. Furthermore, these data suggests that the potential negative impacts of diagnosis concealment (e.g., psychosocial outcomes such as loneliness and self-efficacy) (Kever et al., 2022) may be mitigated by a favorable diagnostic experience, and provider attention to the topic of disclosure throughout the MS disease course. Although a number of studies have investigated the diagnosis experience in MS (Solani et al., 2007; Giordano et al., 2011; Koopman and Schweitzer, 1999; Johnson, 2003; Heesen et al., 2003; Janssens et al., 2003; Isaksson and Ahlström, 2006), there have been few tools validated for evaluating this experience (Solari et al., 2010) or data supportive of effective interventions (Solari et al., 2010; Köpke et al., 2014; Giordano et al., 2014; Thomas et al., 2006) to optimize this critical clinical encounter (Aoun et al., 2016). To our knowledge, this is the first report linking disclosure and concealment to diagnosis experience in MS; future work exploring this relationship is warranted. In addition, elevation of provider awareness and the evaluation of approaches to communication (e.g., the need to implement a more person-centered approach to caring for patients right from the diagnosis stage, shifting focus to the person's values, preferences, cultural, psychosocial, and existential concerns (Aoun et al., 2018)) surrounding disclosure and concealment in MS care may present an opportunity to mitigate these potential (future) effects of the diagnostic experience. Indeed, we report that most MS patients have never been asked about disclosure and concealment by their MS provider, and patients whose provider had discussed these issues were more likely to anticipate positive consequences of disclosure in both personal and professional settings. This study highlights the need for future work focused on the complicated and multifarious issues surrounding diagnosis disclosure and concealment for patients with MS.

#### CRediT authorship contribution statement

**V.M. Leavitt:** Conceptualization, Writing – original draft, Data curation. **A.M. Kever:** Formal analysis, Data curation, Writing – review & editing. **S.M. Weinstein:** Formal analysis, Writing – review & editing. **R.T. Shinohara:** Formal analysis, Data curation, Writing – review & editing. **H. Schmidt:** Writing – review & editing. **S.M. Aoun:** Methodology, Writing – review & editing. **A. Solari:** Methodology, Writing –

review & editing. **A.J. Solomon:** Conceptualization, Writing – original draft, Data curation.

#### Declaration of Competing Interest

VML: Advisory Board: Biogen. Non-promotional speaker: Novartis. Compensation for reviewing: National Institutes of Health, Department of Defense. Chief Scientific Officer and cofounder of eSupport Health, PBC.

AMK: Nothing to disclose.

SMW: Nothing to disclose.

RTS: Consulting: Octave Bioscience. Compensation for reviewing: American Medical Association, National Institutes of Health, Department of Defense, Emerson Collective.

HS: Nothing to disclose.

SMA: Nothing to disclose.

AS: Advisory Board: Almirall, Merck. Speaking: Biogen, Merck, Teva.

AJS: Advisory Board: Genentech, Biogen, Alexion, Celgene, Greenwich Biosciences, Horizon Therapeutics, TG Therapeutics. Consulting: Octave Bioscience. Non-promotional speaking: EMD Serono. Research support: Bristol Myers Squibb. Trainee funding: Biogen. Contracted Research: Sanofi, Biogen, Novartis, Actelion, Genentech/Roche. Expert witness testimony.

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#### Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.msard.2022.104373.

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