

1 **Title page**

2

3 **A multinational survey on the workload of nurses caring for people with**  
4 **multiple sclerosis in Europe**

5

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45

46 **Practice points**

47

48 Nurses in Europe caring for people with MS carry out specialised roles such as  
49 symptom management, treatment monitoring, side effect management, and patient  
50 education; however, time constraints often lead to critical tasks being left undone,  
51 highlighting the need for adequate staffing and resource allocation

52

53 Enhancing nursing support through increased staffing, administrative assistance,  
54 psychological support access, and streamlined referrals to multidisciplinary teams  
55 can enable nurses caring for people with MS to focus on specialized care, ultimately  
56 improving the wellbeing of people in their care

57 **Abstract**

58

59 **BACKGROUND:** MS Nurse PROfessional is an educational program designed to  
60 support nurses caring for people with multiple sclerosis (PwMS), serving as a platform  
61 to increase knowledge and share expertise. As part of advocating to improve working  
62 conditions, MS Nurse PROfessional conducted a survey to describe workload  
63 practices of nurses in Europe caring for PwMS, and survey their opinions on potential  
64 solutions to address tasks currently left undone. **METHODS:** The online survey  
65 included questions around demographics, professional background, and workload  
66 management. It was made available in ten languages to MS Nurse PROfessional  
67 community members and other MS nurses. **RESULTS:** 108 nurses from 15 countries  
68 were included. 74% (n=78) of respondents have a caseload >300 PwMS per year,  
69 which equates to a mean average caseload of 516 PwMS per MS nurse. The majority  
70 of nurses (69%) spend between 30 minutes and 3 hours on each consultation,  
71 including follow-up tasks. Nurses dedicate most time to treatment and symptom  
72 management. Work left undone due to time constraints includes clinical trials, social  
73 benefits advice, team consulting, psychological interventions/support, and paperwork  
74 completion. Over half of nurses surveyed have limited administrative support. Findings  
75 indicate that the nursing community is advocating for an increase in the number of  
76 nurse colleagues, increased access to psychological support for the PwMS, the ability  
77 for nurses to refer to a multidisciplinary care team and the ability to independently  
78 prescribe certain medications. **CONCLUSIONS:** This survey of nurses caring for  
79 PwMS provides useful insights into current workload practices and awareness of their  
80 improved management.

81

82 **Introduction**

83

84 Multiple sclerosis (MS) is a chronic autoimmune disorder that affects the central  
85 nervous system, leading to inflammation, demyelination, and neurological  
86 impairment. This progressive disease can cause a range of physical and cognitive  
87 symptoms, significantly impacting quality of life. The severity of this impact should  
88 not be underestimated; a European study found that people with MS (PwMS)  
89 experience rapid decline in health status (a proxy measure for quality of life) starting  
90 from disease onset.<sup>1</sup>

91

92 Nurses caring for PwMS (MS nurses) play a critical role as key members of the  
93 healthcare team. A literature review concluded that the MS nurse is the healthcare  
94 professional (HCP) 'best placed to meet the complex and variable needs of PwMS,  
95 their families and carers'.<sup>2</sup> The central role of the MS nurse within the  
96 multidisciplinary team (MDT) is crucial to providing effective care.<sup>3,4</sup>

97

98 Although there is no cure for MS, disease-modifying treatments (DMTs) have been a  
99 crucial part of the MS multidisciplinary approach for the last 30 years. Whilst DMTs  
100 can reduce relapse rates and slow progression, they may not benefit everyone due  
101 to being predominantly targeted at people with relapsing forms of MS.<sup>5</sup> DMTs have  
102 evolved considerably since their introduction and have had a significant impact on  
103 both PwMS and service provision.<sup>6</sup> As the number of people diagnosed with MS has  
104 increased and the number and complexity of DMTs available has evolved, the  
105 demand on MS services and clinicians has also grown.<sup>7</sup> MS nurses are essential in

106 facilitating the choice of DMT, reporting and managing side-effects and ensuring  
107 effective monitoring.<sup>8</sup>

108

109 People with more advanced MS have limited treatment options and are reliant on  
110 MDT support and symptomatic management. Demands on MS nurses are  
111 increasing, driven largely by the expanding numbers and needs of PwMS who are  
112 prescribed DMTs. As MS nurses become more focused on DMT provision, their  
113 availability for people with advanced MS has diminished.<sup>9</sup> These people are at high  
114 risk of developing MS-related complications (e.g. recurrent urinary infections), which  
115 can lead to increased need for unscheduled care.<sup>10</sup> Effective management of MS  
116 symptoms, facilitated by an MS nurse, has been shown to reduce the need for  
117 unscheduled care, helping to reduce costs and patient burden.<sup>3,11,12</sup>

118

119 Research has called for MS nurses to be at the center of MS Care Units, alongside  
120 neurologists.<sup>3,4,12 13</sup> A consensus report also emphasized the central role MS nurses  
121 play in acting as care coordinators, offering tailored support and bridging the gap  
122 between PwMS and other HCPs, particularly neurologists.<sup>14</sup>

123

124 Despite acknowledgement of the economic benefits MS nurses can bring,<sup>14,15</sup>  
125 mapping has clearly shown that there are insufficient nurses available to meet the  
126 needs of PwMS.<sup>7,9</sup> Simultaneously, the prevalence of MS is increasing globally.<sup>16</sup>  
127 Across Europe, the number of PwMS was estimated to be 133 per 100,000  
128 population in 2020.<sup>17</sup> As the prevalence of MS continues to increase and the  
129 complexity of DMTs continues to evolve, the shortage of MS nurses is likely to  
130 become more pronounced, leading to greater demands on their services.

131

132 MS Nurse PROfessional (MS Nurse PRO) is an online educational program and  
133 community developed to support MS nurses across Europe, led by the European  
134 Multiple Sclerosis Platform (EMSP).<sup>18</sup> With more than 1,300 annual active members,  
135 across 56 countries, it serves as a resource to increase knowledge, enhance skills,  
136 and foster the sharing of expertise among nurses and other HCPs working with  
137 PwMS.

138

139 MS Nurse PRO recognizes the vital role MS nurses play and the impact a shortage  
140 of MS nurses can have on PwMS. The aim of this study was to describe current  
141 workload practices of MS nurses and their opinions on potential solutions to address  
142 tasks that are currently left undone, in order to better understand this issue across  
143 Europe.

144

## 145 **Methods**

146

### 147 **Design, development and pre-testing**

148 Developed by the Scientific Committee of MS Nurse PRO, the online survey included  
149 15 multiple choice and two open-ended questions around demographics,  
150 professional background, and workload management in the care of PwMS. To  
151 assess time allocated to specific tasks and work left undone, quantitative questions  
152 were incorporated based on the most common interventions identified in prior  
153 research conducted in the UK.<sup>19</sup> Target participants were MS nurses working in  
154 Europe.

155

156 The questions were reviewed by board members of the Rehabilitation in Multiple  
157 Sclerosis (RIMS) network and the survey was piloted by six randomly selected  
158 nurses from the MS Nurse PRO community with more than five years of experience  
159 working as an MS nurse. Once validated, the survey was made available using the  
160 SurveyMonkey© platform in ten auto-translated languages (see Figure,  
161 Supplemental Digital Content 1, for full details of the online survey).

162

### 163 **Sample**

164 A convenience sampling method was applied. All MS Nurse PRO community  
165 members were invited to participate through an online link. The link was emailed to  
166 the MS Nurse PRO database of +6000 nurses and published in a blogpost on the  
167 MS Nurse PRO website. Communication materials about the study were also shared  
168 and transmitted via professional networks to reach as many other MS nurses as  
169 possible. Respondents were asked to complete the survey in one sitting without the  
170 option to close the survey. Submitting the survey implied consent for data  
171 processing. Additional contextual information on the survey was made available in  
172 the invitation email and blogpost. The IP address of the client computer was used to  
173 avoid duplicate entries from the same respondent. The Steering Committee of MS  
174 Nurse PRO served as review board for the survey.

175

### 176 **Statistical analysis**

177 The survey ran from February 1<sup>st</sup>, 2024, to June 30<sup>th</sup>, 2024 and results were  
178 analyzed using Microsoft Excel ©. From the 127 responses received, 108 responses  
179 were retained for analysis; nine entries were removed as they were from outside

180 Europe and 10 entries were removed as the respondents declared they were retired,  
181 working in a profession other than nursing or working as a nurse in rehabilitation.

182

183 The multiple-choice questions were analyzed via pivot tables using absolute, relative  
184 and cumulative frequencies. The majority of questions used a Likert scale of 1–10  
185 points. Responses to these questions were categorized into three groups: low  
186 agreement (rating of 1–3 points), moderate agreement (rating of 4–7 points), and  
187 high agreement (rating of 8–10 points). This categorization enhanced the clarity and  
188 readability of the results.

189

## 190 **Results**

191

### 192 **Work-related characteristics**

193 The respondents were from 15 different European countries with the majority  
194 working in Belgium (n=15), United Kingdom (n=12), Poland (n=12), France (n=10),  
195 Netherlands (n=10), Spain (n=9), Hungary (n=8), Italy (n=8), Czech Republic (n=7)  
196 and Germany (n=6). Least represented countries were Switzerland (n=4), Türkiye  
197 (n=3), Ireland (n=1), Romania (n=1) and Sweden (n=1).

198

199 Of the respondents, 44% indicated working full time with PwMS, 24% were working 4  
200 days/week with PwMS, 12% were working 2.5 days/week with PwMS and the  
201 remainder (20%) were working <2.5 days/week with PwMS.

202

203 Almost half of participants (45%) have worked as a nurse for >25 years, while 25%  
204 have been in the profession for between 16 and 25 years and 25% for between 6

205 and 15 years. Four participants (4%) have between 1 and 5 years of professional  
206 experience and only one respondent (1%) has worked as a nurse for less than one  
207 year.

208

209 Hospital was the most common work setting reported (58%); a total of 35% of nurses  
210 work in a specialized MS center or MS rehabilitation center, and 7% work in other  
211 types of centers.

212

### 213 **Workload of respondents**

214 Approximately one-third of respondents (32%) reported managing a caseload of  
215 301–500 PwMS annually, while 20% had a caseload of 101–300 PwMS, and 17%  
216 reported a caseload of 501–700 PwMS per year. The remaining 31% of respondents  
217 reported caseloads of either fewer than 100 or more than 700 PwMS annually  
218 (Figure 1). Excluding outliers (caseloads of <100 and >1500) and using the average  
219 caseload for each interval (e.g., 200 for the 101–300 range), the mean average  
220 caseload per MS nurse is 516 (standard deviation 408) PwMS (see Table,  
221 Supplemental Digital Content 2, for more information about how the adjusted  
222 caseload was calculated).

223 .

### 224 **Figure 1** Worktime-adjusted caseload of PwMS (n=106)

225

226 Respondents were asked how often they see the same PwMS within a year.

227 Responses were varied with 44% reporting seeing the same PwMS two to three  
228 times a year, 26% four to five times a year, 19% more than five times a year, and  
229 11% only once a year.

230

231 In terms of time spent on each consultation, the majority of respondents (42%)  
232 reported spending between 30 and 60 minutes, including any follow-up tasks.  
233 Approximately a quarter (27%) spend between one and three hours, while 22%  
234 spend less than 30 minutes per consultation. A smaller proportion of respondents  
235 spend between three and five hours (5%) or between five and eight hours (4%) per  
236 consultation.

237

238 Approximately one-third of respondents (38%) indicated that PwMS are seen by a  
239 neurologist, although not at every consultation, while 21% indicated that PwMS are  
240 seen by a neurologist at every consultation. One-third of respondents (33%)  
241 confirmed that PwMS are seen by another member of the MDT (other than a nurse  
242 or neurologist), but not at every visit, while 8% confirmed that they are always seen  
243 by other HCPs.

244

245 Almost half (43%) of respondents indicated they have no access to administrative  
246 support for tasks such as data input and medication administration, whilst 13% have  
247 access to one full-time equivalent (FTE) administrative support. Other levels of  
248 support varied and included 2% with 4/5 FTE, 3% with 3/5 FTE, 12% with 2/5 FTE,  
249 11% with 1/5 FTE, and 17% with 1/10 FTE.

250

251 A majority of respondents allocate 16% or more of their working time to six key  
252 activities (Table 1): completing necessary paperwork (66%), treatment  
253 selection/monitoring and management of side effects (65%), symptom management  
254 (61%), educating the PwMS (54%), and diagnostic procedures (54%). A large

255 proportion of respondents indicated they invest less than 5% of their working time in  
256 clinical trials and research (66%), social interventions/benefits advice (65%) and  
257 team consulting (46%).

258

259 **Table 1** A. Percentage of time assigned to activities related to work with PwMS  
260 (n=108); B. Work left undone by nurses caring for PwMS (undone = not able to  
261 complete due to lack of time or other reasons) (n=108); C. Priority of potential  
262 solutions to decrease the work left 'undone' (n=108)

263

264 Respondents reported a substantial volume of work left undone in two main areas  
265 (Table 1): clinical trials (e.g., interactions with the study nurse) (25% scored 'high')  
266 and social interventions/benefits advice (21% scored 'high'). In addition, the  
267 following work areas scored relatively high in terms of work left undone, with  
268 between 40% and 50% of respondents rating these areas as 4-7 (medium) or 8-10  
269 (high): team consulting (14% scored 'high'), completing necessary paperwork (13%  
270 scored 'high') and psychological interventions/support (12% scored 'high').

271

272 A large majority of respondents (>65%) indicated that the following tasks are  
273 primarily not left undone (scored 'low'): symptom management (81%),  
274 monitoring/recommend medication and side effects (80%), diagnostic procedures  
275 (79%), educating the PwMS and their relatives (73%) and referrals to other HCPs  
276 (69%).

277

278 Increasing the number of nurses (56%), increasing access to psychological support  
279 for PwMS (53%) and enabling referrals to an MDT (52%) were the three most highly  
280 scored solutions (score 8–10) by respondents to ease the workload of MS nurses.  
281 Six possible solutions were given a high score by more than 40% of respondents:  
282 Increased access to a physiotherapist (47%), ability to independently prescribe  
283 certain medications (43%), ability to independently request specific investigations  
284 (42%), improved access to effective databases and software (41%), and increased  
285 access to an occupational therapist and administrative support (both 40%). Lower  
286 priorities for respondents to ease the workload of MS nurses included being able to  
287 refer PwMS to an emergency care pathway, increased access to a social worker or a  
288 reduced number of different support schemes to administer.

289

## 290 **Discussion**

291

292 This survey provides valuable insights into the workload of MS nurses. The results  
293 reveal an important level of specialization in tasks such as treatment monitoring,  
294 management of side effects, symptom management, patient education, and  
295 performing diagnostic procedures, reinforcing previously conducted research.<sup>3,8,14,20</sup>  
296 The survey also underscores a key concern expressed in earlier research that,  
297 despite the acknowledged expertise of MS nurses in Europe, critical tasks are often  
298 left undone due to time constraints.<sup>19</sup>

299

300 Adding a broader European perspective to UK-specific research,<sup>19</sup> the findings  
301 indicate that tasks such as contributing to clinical trials, providing advice on social  
302 benefits and interventions, consulting with team members, completing necessary

303 paperwork, and delivering psychological interventions are often left undone.  
304 According to the European consensus, many of these tasks, when completed, have  
305 been shown to improve the quality of life for PwMS.<sup>14</sup>

306

307 This survey identifies two main reasons why important tasks might be left undone:

- 308 1. MS nurses face an average caseload of 516 per FTE, which exceeds the current  
309 recommended caseload of 358 per FTE.<sup>21</sup> Recent research suggests that even  
310 the recommended caseload is considered too high.<sup>19</sup>
- 311 2. Completing necessary paperwork consumes a considerable portion of nurse`s  
312 working time, a finding consistent with studies in general nursing.<sup>22,23</sup>

313

314 This survey also presented and weighed potential solutions to ease or redistribute  
315 the workload of MS nurses. The primary suggestion was increasing the number of  
316 nursing colleagues, which aligns with findings from previous research.<sup>7,9</sup> In addition,  
317 this survey supports other possible solutions which could be prioritized, including:  
318 increasing access to psychological support, a physiotherapist, or an occupational  
319 therapist for PwMS; enabling nurses to refer to an MDT; allowing nurses to  
320 independently prescribe certain medications and request specific investigations;  
321 providing nurses with access to effective databases and software; and increasing  
322 access to administrative support for nurses. These potential solutions require  
323 systemic change, echoing findings of previously conducted studies in this  
324 area.<sup>3,14,20,24,25</sup>

325

326 Some limitations were identified. The small sample size restricted the ability to  
327 identify variations based on factors such as the place of work (e.g., by country) or

328 healthcare setting (e.g., clinic vs. private practice). Additionally, the study relied on  
329 self-reported data regarding workload, which may produce different results  
330 compared to observational studies or qualitative studies with focus group  
331 discussions. The study did not collect data regarding the type of MS nurse academic  
332 credentials, which can influence responses, especially between countries.

333

334 In conclusion, this survey highlights the expertise and the challenges faced by MS  
335 nurses and underscores the urgent need for a systemic change to establish  
336 recognized organizational and educational resources and frameworks. These  
337 resources and frameworks would empower MS nurses to provide timely, expert and  
338 cost-effective specialist care and support to those impacted by a diagnosis of MS.

339

340 Building on these insights, the proposed work setting would deliver a larger number  
341 of adequately trained nurses, empowered to prescribe certain medications and  
342 request investigations. These nurses would collaborate with a neurologist and an  
343 administrative assistant, forming an integrated care team for their caseload of  
344 PwMS. The coordination of involvement and referrals to an MDT would be  
345 streamlined, with varying degrees of access to a shared electronic patient record,  
346 with the health data owned by the PwMS. At the core of this MDT would be access to  
347 psychological support and physiotherapy, with the flexibility to call upon an  
348 occupational therapist or social worker when necessary.

349

350 Further international research is required to confirm and refine optimal workload  
351 management strategies for MS care teams as well as their information technology  
352 infrastructure to ensure efficient practice management and effective referrals to other

353 HCPs. This research should also consider variations in healthcare delivery cultures,  
354 work settings, and existing training programs and task definitions.

355

356

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404

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492 **Supplemental Digital Content 1. Copy of the online survey**

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494 **Supplemental Digital Content 2. Calculation of worktime adjusted caseload**

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