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Access and use of clinical services and disease-modifying therapies by people with progressive Multiple Sclerosis in the United Kingdom

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1 **Title:** Access and use of clinical services and disease modifying therapies by people
2 with progressive Multiple Sclerosis in the United Kingdom.

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- 23 **Keywords:** Multiple Sclerosis; Multiple Sclerosis, Chronic Progressive;
24 Rehabilitation; Health Services Access

25 **Practice points**

26 1. Level of access to MS Specialists by people with progressive MS in the UK was
27 high at 95%.

28 2. The most utilised practitioners by participants for their MS were MS specialist
29 Doctor/Nurses, General Practitioners and Physiotherapists.

30 3. Level of access to a regular clinical review was 74%, however, 37% received their
31 review less than annually falling short of the recommended guidelines.

32 **Abstract**

33 **Background:** According to current UK guidelines everyone with progressive MS
34 should have access to an MS Specialist but levels of access and use of clinical
35 services is unknown.

36 **Objective:** To investigate access to MS Specialists, use of clinical services and
37 Disease Modifying Therapies (DMT) by people with progressive MS in the United
38 Kingdom.

39 **Methods:** A UK wide, online survey was conducted via the UK MS Register.
40 Inclusion criteria: age over 18 years, primary or secondary progressive MS and a
41 member of the UK MS Register. Participants were asked about access to MS
42 Specialists; recent clinical service use; receipt of regular review and current and
43 previous DMT use. Participant demographics; quality of life and disease impact
44 measures were supplied from the UK MS Register.

45 **Results:** In total 1298 participants responded: 5% were currently taking DMT; 23%
46 had previously taken DMT; and 95% reported access to an MS Specialist. Most
47 utilised services were: MS Doctor/Nurse (50%), General Practitioner (45%), and
48 Physiotherapist (40%). Seventy-four percent received a regular review although 37%
49 received theirs less than annually. Current DMT use was associated with better
50 quality of life but past DMT use was associated with poorer quality of life and higher
51 impact of disease.

52 **Conclusion:** Access to, and use of, MS Specialists was high. However a gap in
53 service provision was highlighted in both receiving and frequency of regular reviews.

54

55 **Introduction**

56 Multiple Sclerosis (MS) is a chronic inflammatory autoimmune demyelinating disease
57 of the central nervous system resulting in axonal and grey matter loss. It is estimated
58 that there are 130,000 people living with MS in the United Kingdom (UK).¹ At time of
59 diagnosis, approximately 15% of people with MS are diagnosed with Primary
60 Progressive MS (PPMS), 80% with Relapsing Remitting MS (RRMS) and 5% with
61 Progressive Relapsing MS; and approximately 80% of those with RRMS will go on to
62 develop Secondary Progressive MS (SPMS).²

63 Disease Modifying Therapies (DMT) are currently available to those who have
64 RRMS, or are still experiencing relapses in the early stages of SPMS. Disease
65 modifying therapies have been found to delay the transition from RRMS to SPMS.³
66 However, there are currently no effective licensed pharmacological treatments for
67 slowing the progression of disability in both primary and secondary progressive MS,
68 although Ocrelizumab has been shown to decrease disability progression by 25% in
69 people with primary progressive MS.³ Due to the lack of available effective
70 pharmacological treatments for disease activity in progressive MS, specialist
71 rehabilitation services are of particular importance. Despite this, access to specialist
72 services throughout the UK can be difficult, and people with progressive MS are
73 often told that there is little available for them, and advised to self-manage their
74 condition.⁴ The International Progressive MS Alliance have subsequently highlighted
75 rehabilitation for people with progressive MS as a research priority,⁵ and disciplines
76 such as physiotherapy have positive evidence in the rehabilitation of people with
77 progressive MS.⁶

78 The current National Institute for Health and Care Excellence (NICE) guidelines for
79 multiple sclerosis and Healthcare Improvement Scotland clinical standards for
80 Neurological Health Services state that everyone with MS in the UK should have
81 access to an MS Specialist and receive a comprehensive regular review at least
82 annually, by a member of the multi-disciplinary MS team.^{7,8} This review should cover
83 all aspects of care including medication; symptom management; disease course;
84 general health; participation and social care needs and does not have to be
85 conducted in a clinical environment. Recently, MS Specialist Nurses were found to
86 be the most consulted health care professional⁹ and 86% of people with MS
87 reportedly had access to a Neurologist or MS Nurse.¹⁰ However, these studies did
88 not differentiate between MS types. In some areas within the UK, such as London
89 and Northern Ireland, a limited MS service provision has been found.^{11,12} Furthermore
90 in England and Wales 55% of patient comments regarding provision of NHS MS
91 services were negative.¹³

92 The purpose of this study was to investigate access to, and use of, clinical services
93 for people with primary and secondary progressive of MS. Specifically exploring
94 whether people with progressive MS had access to an MS Specialist; what clinical
95 services they used; if they received an regular review; their current and previous use
96 of DMT and to explore any associations between these variables and quality of life
97 and physical and psychological impact of MS.

98

99 **Methods**

100 The UK MS Register is an online register funded by the MS Society. People with MS
101 become members voluntarily, and answer both regular and online surveys.¹⁴

102 Members self-report their MS diagnosis type, demographical information and
103 complete self-report outcome measures, such as the EQ-5D-3L Health
104 Questionnaire (EQ-5D-3L) and the physical and psychological sub-scales of the
105 Multiple Sclerosis Impact Scale-29 version 2 (MSIS-29) every three months. Data
106 are anonymised using the Secure Anonymised Information Linkage system.¹⁵ At the
107 time of this study there were 11,041 people on the UK MS Register with 4,384
108 people active on the Register in the previous six months.

109 *Design and participant recruitment*

110 A cross-sectional survey design was used. The survey was available on the UK MS
111 Register from August to October 2015. To be eligible for inclusion a participant had
112 to be 18 years old or over, living in the UK, diagnosed with progressive MS and
113 registered on the UK MS Register. Potential participants were identified by the UK
114 MS Register, and emailed informing them of the survey. The survey was accessed
115 only via the UK MS Register, and completion was regarded as informed consent.
116 Ethical approval was obtained from the College of Medical, Veterinary & Life
117 Sciences Ethics Committee, University of Glasgow and the study underwent peer
118 review by the information governance panel of the UK MS Register (South West -
119 Central Bristol Research Ethics Committee, Ref: 11/SW/0160).

120 The survey was in two sections. The first asked about access to, experiences and
121 opinion of physiotherapy services and complementary therapies in the UK, and has
122 been described elsewhere.¹⁶ The second section asked if a participant had access to
123 an MS Specialist: defined as a clinician with MS Specialist skills. Participants were
124 also asked which clinicians they used in the previous three months for their MS.
125 Participants were asked if they received a regular review for their MS; how often that

126 review took place; who normally undertook the review; and where the review
127 normally took place. Finally, previous and current use of DMT was explored and
128 participants were asked to select whether they were currently taking, or had
129 previously taken, any of the following: Beta-interferon (Rebif, Avonex, Betaferon),
130 Glatiramer acetate (Copaxone), Dimethyl fumarate (Tecfidera), Teriflunomide
131 (Aubagio), Natalizumab (Tysabri, Antigren), Fingolimod (Gilenya, Novartis),
132 Mitoxantrone (novantrone), and Alemtuzumab (Lemtrada). A copy of the survey is
133 available on request. Due to the structural progression of the survey not all
134 participants answered all questions.

135 *Access*

136 This study explored two components of access: the opportunity to enter into the
137 service (regardless of organisational barriers such as waiting times and distance to
138 travel) and the utilisation of services.¹⁷ In this survey these two terms were referred
139 to as 'access' and 'use' respectively. Whilst these terms were not explicitly
140 explained the meaning was implied by questions asked, for example "Which of the
141 following clinicians could you see if you wanted to?" implied the availability of the
142 opportunity to see a clinician and "Which of the following clinicians have you seen in
143 the past three months for your MS?" implied the utilisation of services. Barriers to
144 accessing physiotherapy were explored in some detail and have been published
145 elsewhere.¹⁶

146 *Access to an MS Specialist*

147 Participants were asked if they had access to an MS Specialist service. If they
148 answered 'yes' they were then asked which clinicians they had seen recently for their
149 MS. If they answered 'no' they were then asked which clinicians they could see if

150 they wanted to. Included in this list were 'MS Specialist Nurse' and 'MS Specialist
151 Doctor/ Neurologist'. The answers of those who reported having access to an MS
152 Specialist service and of those who reported they could see an MS Specialist Nurse
153 or Doctor were combined. This gave the total level of access to MS Specialists of
154 this cohort.

155 *Additional data from UK MS Register*

156 In addition to data collected from the survey, the following data routinely collected by
157 the UK MS Register were accessed: type of MS; age; gender; time since diagnosis
158 of MS; quality of life measured by the EQ-5D-3L; the physical and psychological sub-
159 scales of the MSIS-29; Lower Super Output Area codes [England and Wales] and
160 Output Area codes [Scotland] (there were no available geographical data for
161 participants from Northern Ireland). Lower Super Output Area codes and Output
162 Area codes, which are used to tabulate census and statistical data by the Office of
163 National Statistics, were combined with data available from the Office for National
164 Statistics and the Scottish Office for National Statistics^{18,19} to generate the following:
165 rural or urban dwelling, and Strategic Health Authority for participants in England (in
166 2013 NHS England divided England into ten regions called Strategic Health
167 Authorities each of which contained multiple NHS trusts). Rural dwelling was defined
168 as a settlement with a population of 10,000 or less.²⁰

169 The EQ-5D-3L is a self-report measure of quality of life generating an index ranging
170 from -1 to 1, a higher index indicating a better quality of life.²¹ The MSIS-29 is a 29-
171 item self-report measure with physical and psychological sub-scales to measure the
172 impact of MS.²² The physical sub-scale ranges from 20-80 and the psychological
173 sub-scale ranges from 9-36. A lower score indicates a lower impact of MS.

174 *Data analysis*

175 Data were analysed using IBM SPSS v22. Descriptive statistics were used to
176 characterise demographic data and all outcome variables. The responses to
177 individual questions are presented as percentages. Data were tested for normality
178 and due to non-normal distribution Chi-square and Mann-Whitney tests were used
179 as appropriate. A significance level of $p < 0.05$ was used.

180

181 **Results**

182 In total 2,538 registrants with progressive MS were emailed by the UK MS register,
183 and 1,298 participants completed the survey generating a 51% response rate;
184 England (n=1,030), Scotland (n=130), Wales (n=104) and Northern Ireland (n=21).
185 Participants had a mean age of 59 (SD 8) years and time since diagnosis of 16 (SD
186 9) years; the female to male ratio was 1.7: 1; 37% had PPMS (n=486) and 63% had
187 SPMS (n=812). Mean EQ-5D-3L index was $0.49 \pm$ SD 0.2, indicating a poorer quality
188 of life compared to general population of the same age who would have an
189 approximate index of 0.8.²³ The mean MSIS-29 physical and psychological sub-
190 scores were 55.97 (SD 12.64) and 19.96 (SD 6.10) respectively indicating that this
191 sample was moderately affected both physically and psychologically by their MS
192 (Table 1). Compared to those with SPMS, people with PPMS were younger, had a
193 shorter time since diagnosis, had a higher EQ-5D-3L index and lower psychological
194 and physical scores on the MSIS-29 (all $p < 0.005$).

195 In total 95% (n=1,184) of participants reported that they had access to an MS
196 Specialist, and 96% (n=959) of those who had access reported they would be able to

197 access the specialist if their symptoms or needs changed. Figure 1 shows access to
198 MS Specialists across the UK. Access to an MS Specialist ranged from 92% in
199 Yorkshire and the Humber and the East Midlands to 98% in Wales.

200 Overall, 81% (n=1046) of participants reported using clinical services for their MS in
201 the previous three months. The most commonly used clinical services were MS
202 Specialist Doctor/Nurse (50%, n=517), General Practitioner (45%, n=467), and
203 Physiotherapist (40%, n=414) (Figure 2). Of the participants receiving clinical
204 services for their MS: 46% (n=481) were receiving a single service and 54% (n=565)
205 were receiving more than one service. From those who answered the question 20%
206 (n=88) of participants reported they were currently taking DMT (PPMS n=18, SPMS
207 n=70), and 24% (n=303) reported that they had previously taken DMT (PPMS n=37,
208 SPMS n=266). These numbers equated to 5% and 23% of the total sample
209 respectively.

210 In total, 74% (n=917) of participants received a regular review; 56% (n=505)
211 received that review annually; 63% (n=569) had their review performed by an MS
212 Specialist Doctor and 27% (n=248) reported it was performed by a nurse. A total of
213 90% (n=819) reported usually receiving their review in a hospital or clinic (Table 2).
214 Ninety percent of participants who were currently taking a DMT received a regular
215 review: 6% received their review twice a year, 51% once a year, 41% less frequently
216 than once a year and 2% did not know (not shown in tables).

217 There was a statistically significant association between access to an MS Specialist
218 and receiving a regular review ($p<0.001$) (Table 3). Access to an MS Specialist was
219 not associated with MS type, past or present DMT use, or urban/rural dwelling (Table
220 3).

221 Participants who were in receipt of a single clinical service, as opposed to multiple
222 services, for their MS had a better quality of life as measured by the EQ-5D-3L index
223 ($p<0.001$), and less of a physical and psychological impact of MS as measured by
224 the MSIS-29 ($p<0.001$). Use of single or multiple services was, however, not
225 dependent on MS type ($n=1045$, $p=0.165$) or whether a participant lived in a rural or
226 urban location ($n=1003$, $p=0.972$) (not shown in tables). Participants who were
227 currently taking DMT for their MS had a better quality of life ($p=0.016$) than those
228 who were not taking DMT. Those who had previously taken DMT, however, had a
229 poorer quality of life ($p<0.001$), and greater physical ($p<0.001$) and psychological
230 ($p=0.006$) impact than those who had not taken DMTs (Table 4). There were no
231 differences in quality of life and disease impact scores between those who did and
232 did not have access to an MS Specialist or access to a review and there was no
233 difference in the psychological or physical impact of MS between those who were
234 and were not currently taking DMT (Table 4).

235

236 **Discussion**

237 This study had the largest sample solely of people with progressive MS to be
238 surveyed to date, and was the first to investigate access to, and use of clinical
239 services for people with progressive forms of MS across the UK.

240 In this sample of 1298, access to an MS Specialist was high (95%) and was similar
241 across the UK (Figure 1). This was slightly higher than the outcome of a survey
242 carried by the MS Society in people with all types of MS in the UK which reported
243 86% of participants had access to a Neurologist or MS Nurse.¹⁰ A previous study
244 conducted in London reported a lack of access to MS related services amongst

245 those severely affected by MS¹¹ however the present study indicates that 95% of
246 people with progressive MS have access to an MS Specialist. This difference in
247 results may indicate improvements in service provision, since Edmonds et al.¹¹
248 carried out their study and that the people in this sample were not severely affected
249 by their MS. Interestingly there were no differences in quality of life and disease
250 impact measures between those who did and those who did not have access to an
251 MS Specialist. However, there were only a relatively small number of people who
252 did not have access in these analyses so results should be interpreted with caution.

253 While access to MS Specialists was high not all received a regular review, as is
254 recommended by current guidelines and standards.^{7,8} Just under three quarters of
255 participants received a regular review and 37% of these received their review less
256 frequently than annually. This is a breach of the National Institute for Healthcare and
257 Excellence guidelines and the Healthcare Improvement for Scotland clinical
258 standards. With the potential advent of pharmacological treatments for PPMS
259 disease activity³ a regular clinical review will in the future be particularly important in
260 the care of people with progressive MS. Indeed of those who were currently
261 receiving a DMT 90% were in receipt of a regular review but only 57% received that
262 review once a year or more frequently. However, it should be noted that there were
263 no differences in quality of life or disease impact measures between those who did
264 and did not receive a regular review.

265 Use of clinical services in this study's participants was high. The three most utilised
266 clinical services were, MS Specialist Nurse or Doctor, General Practitioner, and
267 Physiotherapist (Figure 2). This finding was similar to two previous studies surveying
268 people with all types of MS in the UK and in Europe.^{9,24} This may indicate that

269 people with progressive MS are using the same kind of clinical services to those with
270 RRMS.

271 Similar proportions of participants received multiple services (54%) or a single
272 service (46%) for their MS. Those who received a single service for their MS had a
273 better quality of life and lower psychological and physical impact of MS compared to
274 those who received multiple services which may be a reflection of clinical need and
275 in turn likely to be associated with disability level.

276 There was no association between rural or urban dwelling and access to an MS
277 Specialist or receiving a regular review. Previous research by Lonergan et al. in the
278 Republic of Ireland found a lack of access to services was associated with rural
279 dwelling.²⁵ These researchers however surveyed people with all types of MS, and in
280 addition 37% of the population live rurally in the Republic of Ireland, compared to
281 18% in the UK²⁶ which may explain the differences in results reported. Furthermore,
282 the lack of association between rural and urban living and access to an MS
283 Specialist may be due to the definition of access used in this study being the
284 opportunity to see a clinician regardless of personal and organisational barriers.

285 Five percent of this sample was currently taking DMT and 23% had been prescribed
286 them previously. This result is lower than previously reported by the MS Society
287 which found 56% of all people with all types of MS in UK were taking DMT.¹⁰ This
288 difference is expected as prescribing guidelines state that DMT are not effective in
289 progressive forms of MS when relapses are not present ²⁷ and that those on DMT
290 currently may have been prescribed them whilst in the relapsing remitting phase of
291 MS. The five percent of participants still taking DMT does however, contribute
292 further to the importance of a regular clinical review as there are potentially a large

293 number of people with MS inappropriately taking these drugs in the UK.
294 Furthermore those taking DMT had a better quality of life compared to those who
295 were not. Those who had previously taken DMT however, had a poorer quality of life
296 and a greater physical and psychological impact of MS compared to those who had
297 never taken them. These differences were however small and may be an indication
298 of the stage of disease, as those who are no longer taking DMT may have more
299 advanced disease, and transitioned into the secondary progressive phase for which
300 DMT are no longer appropriate.

301 *Study Limitations*

302 The open and voluntary nature of the UK MS Register and online surveys leave the
303 sample open to bias to the motivated and those with a vested interest. In addition
304 those who are more severely disabled and find it difficult to access services may not
305 be on the register. The diagnosis and type of MS was self-reported, however in
306 future the UK MS Register will be linked with clinical data from the NHS. The concept
307 of access is multi-faceted and even though the definition of access as the
308 opportunity to see a clinician was implied by the questions asked, it was not implicitly
309 defined which may have affected responses. For example if they felt that even their
310 clinician was not available due to a long waiting list they may have selected that they
311 did not have access. A programming error lead to the responses regarding access
312 and use of MS Doctor and MS Nurse being combined and were thus combined in the
313 results. There were no geographical data available for participants in Northern
314 Ireland which limited the analysis comparing participants living in a rural and urban
315 setting. Participants may have encountered problems with memory recall when
316 asked regarding the regularity of review. This may have resulted in errors in
317 reporting with those who more recently received their review being more likely to

318 report it. Lastly due to the conditions of ethical approval it was not possible to
319 examine the demographics of those who did not respond to the survey to determine
320 if they were typical of those registrants of the UK MS Register with progressive MS.

321

322 **Conclusion**

323 This was the first survey of its kind examining access and use of clinical services by
324 people with progressive MS in the UK, and had the largest sample of people with
325 progressive MS to date. Access to an MS Specialist was high and use of clinical
326 services for participant's MS was also high. However a gap in service provision,
327 which is breaching national guidelines, was found in relation to regular reviews and
328 health care providers in the UK should address this. Furthermore investigation
329 should also establish the effectiveness and patient satisfaction of services used.

330 **Disclosures/ Conflict of interest**

331 The Authors declare there is no conflict of interest.

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405

406

Table 1. Demographics of survey participants.

	Total (n=1298)	PPMS (n=486)	SPMS (n=812)	Difference between PPMS and SPMS
Age (years)	59 (8)	60 (8)	58 (9)	$p<0.001^a$
TSD (years)	16 (9)	12 (8)	19 (9)	$p<0.001^a$
Gender				
<i>Female</i>	824	246	578	$p<0.001^b$
<i>Male</i>	474	240	234	-
Country [where known]				
<i>Scotland</i>	130	57	73	$p=0.343$
<i>England</i>	1030	372	658	-
<i>Wales</i>	104	40	64	-
<i>N. Ireland</i>	21	9	12	-
EQ-5D-3L index	0.49 (0.20)	0.52 (0.20)	0.48 (0.20)	$p=0.001^a$
MSIS-29 psych	- 19.96 (6.10)	19.35 (6.05)	20.31 (6.11)	$p=0.004^a$
MSIS-29 phys	- 55.97 (12.64)	54.46 (13.27)	56.88 (12.12)	$p=0.002^a$

408 Abbreviations: n: number of responses; TSD: Time Since Diagnosis; EQ-5D-3L: EQ-
 409 5D-3L Health Questionnaire; MSIS-29 psych: Multiple Sclerosis Impact Scale-29
 410 psychological sub-scale; MSIS-29 phys: Multiple Sclerosis Impact Scale-29 physical
 411 sub-scale

412 Figures where applicable are mean and SD. Not every participant had demographic
 413 data available, for example country of domicile. Mean time between survey
 414 completion and most recent EQ-5D-3L and MSIS-29 completions were 39 (120) and
 415 19 (111) days.

416 ^aStatistically significant as calculated by Mann-Whitney tests.

417 ^bStatistically significant as calculated by Chi-square test.

418

419 Table 2. Survey responses regarding a regular review for progressive MS.

Question	Answer	n	%
Are you offered a regular clinical review for your MS? (n=1243)	Yes	917	74
	No	287	23
	Don't know	39	3
On average; how often is your review? (n=912)	Twice a year	57	6
	Once a year	505	55
	Less frequently than once a year	341	37
	Don't know	9	1
Who usually undertakes your review? (n=911)	MS Specialist Doctor/Neurologist	569	63
	GP	8	1
	Nurse	248	27
	Physiotherapist	12	1
	Occupational therapist	6	1
	The person can vary	58	6
Where does your review normally take place? (n=911)	Other	10	1
	At home	43	5
	In a hospital or clinic	819	90
	In a community centre	10	1
	GP surgery	20	2
	Other	19	2

420 Abbreviations: n: number of participants; GP: General Practitioner.

421

422

423 Table 3. Associations between access to an MS Specialist and MS type, past and
 424 present DMT use, rural or urban living and receiving a regular review.

	n	<i>p</i>
Access to MS Specialist and PPMS or SPMS	1248	0.473
Access to MS Specialist and past DMT use	1227 ^a	0.371
Access to MS Specialist and current DMT use	362 ^a	0.175
Access to MS Specialist and urban/rural dwelling	1201	1.000
Access to MS Specialist and regular review	1233	<0.001 ^b

425 Abbreviations: n: number of responses; PPMS: Primary Progressive Multiple
 426 Sclerosis; SPMS: Secondary Progressive Multiple Sclerosis; DMT: Disease
 427 Modifying Therapies.

428 ^an is significantly higher than results of current and past DMT use reported in main
 429 text (88 and 303 respectively) as Chi-square test also includes the participants who
 430 answered no.

431 ^bStatistically significant result from Chi-square test.

432

433 Table 4. Differences in EQ-5D-3L and MSIS-29 scores in those with and without
 434 access to a MS Specialist, regular review, receiving more than one MS service, and
 435 current and past DMT use.

Access to MS specialist	yes		no		<i>p</i>
	n	med	n	med	
EQ-5D-3L index	1154	0.57	62	0.50	0.245
MSIS-29 phys	1180	56.00	64	58.50	0.581
MSIS-29 psych	1167	19.00	63	19.00	0.832
Access to review	Yes		no		<i>p</i>
	n	med	n	med	
EQ-5D-3L index	898	0.57	276	0.57	0.642
MSIS-29 phys	914	56.00	286	58.00	0.187
MSIS-29 psych	903	19.00	285	19.00	0.410
Single/multiple services	single		multiple		<i>p</i>
	n	med	n	med	
EQ-5D-3L index	469	0.57	548	0.50	<0.001 ^a
MSIS-29 phys	478	55.00	563	59.00	<0.001 ^a
MSIS-29 psych	473	18.00	555	20.00	<0.001 ^a
Current DMT use	yes		no		<i>p</i>
	n	med	n	med	
EQ-5D-3L index	87	0.57	346	0.50	0.016 ^a
MSIS-29 phys	87	56.00	359	60.00	0.050
MSIS-29 psych	85	20.00	357	20.00	0.960
Past DMT Use	yes		No		<i>p</i>
	n	med	n	med	
EQ-5D-3L index	296	0.50	912	0.57	<0.001 ^a
MSIS-29 phys	302	59.00	935	56.00	<0.001 ^a
MSIS-29 psych	299	20.00	925	19.00	0.006 ^a

436 Abbreviations: n: number of responses; med: median; EQ-5D-3L: EQ-5D-3L Health
 437 Questionnaire; MSIS-29 psych: Multiple Sclerosis Impact Scale-29 psychological
 438 sub-scale; MSIS-29 phys: Multiple Sclerosis Impact Scale-29 physical sub-scale;
 439 DMT: Disease Modifying Therapies

440 Not all participants had EQ-5D-3L or MSIS-29 data available. This accounts for
 441 slight variation in n.

442 ^aStatistically significant as calculated by Mann-Whitney tests.

443

444 Figure 1: Access to MS Specialists across the UK

445

446 Figure 1. Access to MS Specialists by people with progressive MS within Scotland,
447 Northern Ireland, Wales and the Strategic Health Authorities in England.

448

449

450 Figure 2. Clinical services used for MS in the past three months.

451 Figure 2. Clinical services used by participants for their MS in the prior three months.
452 Abbreviations: MSDr/NS: MS Doctor or MS Nurse; GP: General Practitioner; Physio:
453 Physiotherapist; OT: Occupational Therapist; Cont NS: Continence Nurse; NS oth:
454 Nurse other; Dr oth: Doctor other; Orth: Orthotist; SW: Social Worker; Oth: other;
455 Psych: Psychologist; SLT: Speech and Language Therapist; Diet: Dietician
456