

A large, stylized graphic element consisting of a central orange triangle pointing to the right, surrounded by a white outline that forms a larger, rounded shape. The background of the entire page is white with orange geometric shapes and lines.

**My MS My Needs 2016:  
access to treatment and  
health care**

**Technical report**

Diane Redfern-Tofts, Laura  
Wallace and Ann McDougal

Let's stop MS **together**

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## 1. Introduction

The aim of this project was to gather up-to-date information on the health and social care needs of people with MS across the UK and to explore how the MS landscape has changed since the original 'My MS, My Needs' work conducted in 2013<sup>1</sup>. The original project explored the extent to which people with MS needed particular aids, services, treatments and information; and whether or not these needs were being met.

Associations between needs and access for different services were also explored – for example whether or not access to one service was associated with need or access for another service. While the 2016 questionnaire was broadly similar, some questions were changed, removed or added, meaning that comparisons cannot always be made. Furthermore, the samples were different for the two surveys, so while trends can be identified direct comparison is not possible. The 2016 project focused on three broad areas; treatment and health care, employment and financial security, and care and support.

This technical report shows the treatment and health care results from the 2016 survey. The results from the other sections of the questionnaire will be made available in subsequent technical reports.

This report shows results at a UK level, and the four nations of the UK (England, Scotland, Wales and Northern Ireland).

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1. Dorning, H., Luck, G. and Holloway, E. (2013) A lottery of treatment and care: MS services across the UK technical report

## 2. Methodology

### Questionnaire design

The questionnaire was available in both an online and postal format to maximise response rates. A postal survey was distributed to members of the MS Society in February and members had one month to return the completed questionnaire. Members of the UK MS Register and Shift MS were invited to complete the questionnaire online via the MS Register portal. The results were then compiled by the MS Register team at Swansea University into one dataset.

The questionnaire was designed by the MS Society research team<sup>2</sup> and consisted of 40 closed-ended categorical questions on six sides of A4 paper. The online version asked the same questions and was completed via the UK MS Register website. The questions had a mixture of single tick responses and multiple response options. Respondents were asked to reflect on their situation over the past 12 months and all questions were about the respondent.

The questionnaire was split into sections: Background information; Care needs; Employment; Income and benefits; Powered wheelchairs; Health care and community; Care coordination; Access to therapies; Information and advocacy.

The initial drafts of the questionnaire were developed through cognitive interviews with people with MS and relevant content changes were made to question wording, topics and structure. The final version of the questionnaire can be found in Appendix 1.

### Sample

The target population were members of the MS Society, MS Register and Shift MS who had indicated that they had MS, were over the age of 18 and lived in the UK, the Isle of Man or the Channel Islands – 39,434 people in total. The data from respondents in the Isle of Man and the Channel Islands has not been included within the UK analysis and will form no further part of this report.

**In order to account for selection bias within our sample population, we have applied weighting to the final dataset. For further details please see the data analysis section.**

### Survey administration and data entry

The MS Society sample was selected from the MS Society membership database. The sample file included name, postal address and MS Society membership number. Postcodes were used to allocate individuals to health authority areas using postcode

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<sup>2</sup> The questionnaire used one externally designed question (The British Attitudes Survey, 2011. Question 274), and adapted it for the current study to capture respondents' feeling about their income.

look-up files from ONSPD<sup>3</sup> and HSCIC<sup>4</sup>. The sample file was sent securely to a specialist data capture company (Document Capture Company, DCC), under the terms of a data protection agreement. DCC were commissioned by the MS Society to fulfil the logistical elements of the postal survey, including mailing out a cover letter (see Appendix 2), questionnaire and freepost reply envelope to everyone in the sample. Responses were logged against unique identifiers as they were returned. Reminder letters were sent to non-respondents after approximately two weeks. Responses were not linked back to contact details, however they were linked back to geographic and health authority area via the unique identifier. Any copies of the questionnaire erroneously returned directly to the MS Society were forwarded to DCC for data entry.

Questionnaires were posted w/c 8 February 2016 and data collection ended on 22 April 2016.

The postal responses collected and formatted by DCC were transferred via a secure transfer facility to Swansea University using a domain restricted IP transfer facility; the team at Swansea University combined this with the dataset from the online questionnaire. Postcode, age and gender were captured and used to match and remove duplicate responses across online and postal modes.

The MS Register team at Swansea University then structured the raw data into an appropriate format for descriptive and local level analysis, and imported it into IBM SPSS Statistics 22. Further geographical based open source reference data from the ONS was attached based on the responders Lower Layer Super Output Area (LSOA) (derived from their postcode). To avoid duplicate responses, all online and paper correspondence highlighted that if participants received the questionnaire through multiple routes, they should only fill in one questionnaire. In addition, any time the participants had filled in the postal or portal questionnaire more than once, the duplicate entry was removed, with a selection of the most recent complete response chosen.

## Data analysis

Due to age and gender bias in our sample, the data has been weighted using prevalence estimates<sup>5</sup> to be representative of the UK MS population. As the data has been weighted figures are not absolute and have been rounded, meaning that the sum of numbers in the data tables may not add up to the total provided. On individual nation tables which include time since diagnosis, total percentages have not been included to account for multiple responses.

Descriptive statistics were analysed in SPSS with tables created in Excel. Cross-tabs were used to explore relationships between different services and support, for example whether access to one service was related to access to another. For questions with responses relating to 'need' and 'met need', calculations were carried out to produce a 'total need' and 'need met' percentage for those who answered the question. For example, the table below shows mock data for responses to the question regarding access to a neurologist, broken down by the respondents'

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3 <http://www.ons.gov.uk/ons/guide-method/geography/products/postcode-directories/-nsp-/-index.html>

4 <http://systems.hscic.gov.uk/data/ods/datadownloads/onsdata>

5 MS Society estimate based on 2010 incidence and prevalence rates (Mackenzie et al. 2013) adjusted for accuracy based on the assumption that 82% of cases from this study can be validated (estimate based on Alonso et al. 2007). These adjusted rates have been applied to 2014 population estimates (Office of National Statistics).

nation. This allows for the 'Total need' and 'Need met' statistics to be compared between the nations.

'Total need' and 'Need met' statistics have not been calculated for tables where a cross comparison with another question has been conducted. This is to avoid misinterpretation.

		Nation				Total
		England	Northern Ireland	Scotland	Wales	
<b>In the past 12 months, have you seen a neurologist in relation to your MS?</b>	Yes	5 19.2%	5 19.2%	5 19.2%	5 19.2%	20 19.2%
	No, and I have not needed to	6 23.1%	6 23.1%	6 23.1%	6 23.1%	24 23.1%
	No, but I needed to	7 26.9%	7 26.9%	7 26.9%	7 26.9%	28 26.9%
	I am not sure	8 30.8%	8 30.8%	8 30.8%	8 30.8%	32 30.8%
	Total	26 100.0%	26 100.0%	26 100.0%	26 100.0%	104 100.0%
	Total need	46.2%	46.2%	46.2%	46.2%	46.2%
	Need met	41.7%	41.7%	41.7%	41.7%	41.7%

'Total need' is calculated as the proportion of respondents who responded 'Yes' or 'No, but I needed to', out of all of those who answered the question. In this example for the nations in the table 'Total need' is  $(5+7)/26 = 46\%$ .

'Need met' is calculated as the proportion of respondents who responded 'Yes', out of those who responded 'Yes' or 'No, but I needed to'. In the example above for each nation the 'Need met' is calculated as  $5/(5+7) = 42\%$ .

## Respondents

10,888 people with MS responded to the questionnaire.

## Demographic data

The final sample consisted of 8,132 (75%) women and 2,756 (25%) men, which is representative of people with MS in the UK. 44% of respondents had relapsing remitting MS, 12% had secondary progressive MS with relapses, 19% had secondary progressive MS without relapses, 15% had primary progressive MS, and 8% were not sure of their MS type.

### 3. Results

Results of this analysis are presented in tables 1 to 54 of this report. For discussion on the implications of these results and recommendations, please see the national reports available at [www.mssociety.org.uk/accesslottery](http://www.mssociety.org.uk/accesslottery)

#### Survey administration

Table 1 - Collection method by nation

Collection type	Nation				UK
	England	Northern Ireland	Scotland	Wales	
Online	2612 29.0%	135 36.8%	298 31.8%	270 47.0%	3315 30.4%
Postal	6396 71.0%	232 63.2%	640 68.2%	305 53.0%	7573 69.6%
Total	9008 100.0%	366 100.0%	939 100.0%	575 100.0%	10888 100.0%

#### Demographics

Table 2 - Gender

Are you male or female?	Nation				UK
	England	Northern Ireland	Scotland	Wales	
Female	6739 74.8%	277 75.5%	692 73.7%	425 73.9%	8132 74.7%
Male	2269 25.2%	90 24.5%	247 26.3%	150 26.1%	2756 25.3%
Total	9008 100.0%	366 100.0%	939 100.0%	575 100.0%	10888 100.0%

Table 3 - Age

	Nation				UK	
	England	Northern Ireland	Scotland	Wales		
<b>How old are you?</b>	18-29	220 2.4%	11 2.9%	24 2.6%	25 4.3%	280 2.6%
	30-39	969 10.8%	87 23.7%	120 12.8%	79 13.8%	1255 11.5%
	40-49	1922 21.3%	103 28.1%	227 24.2%	142 24.7%	2394 22.0%
	50-59	2527 28.1%	97 26.5%	273 29.1%	150 26.0%	3047 28.0%
	60-69	2206 24.5%	48 13.1%	209 22.3%	119 20.7%	2582 23.7%
	70-79	909 10.1%	18 5.0%	69 7.3%	48 8.3%	1044 9.6%
	80 or over	256 2.8%	2 0.6%	17 1.8%	12 2.1%	287 2.6%
	Total	9008 100.0%	366 100.0%	939 100.0%	575 100.0%	10888 100.0%

Table 4 - Type of MS

	Nation				UK	
	England	Northern Ireland	Scotland	Wales		
<b>What type of MS do you have?</b>	Relapsing remitting MS	3827 43.6%	233 64.9%	431 46.9%	253 44.8%	4744 44.7%
	Secondary progressive MS with relapses	1081 12.3%	29 8.2%	109 11.8%	74 13.1%	1293 12.2%
	Secondary progressive MS without relapses	1821 20.8%	41 11.5%	153 16.6%	101 17.9%	2116 19.9%
	Primary progressive MS	1359 15.5%	37 10.2%	143 15.6%	96 17.1%	1635 15.4%
	I don't know	682 7.8%	19 5.2%	84 9.1%	40 7.1%	824 7.8%
	Total	8770 100.0%	359 100.0%	919 100.0%	564 100.0%	10613 100.0%

Table 5 - Time since diagnosis

How long ago were you diagnosed as having multiple sclerosis by your neurologist?	Nation				UK
	England	Northern Ireland	Scotland	Wales	
	Less than 12 months ago	156 1.8%	15 4.2%	16 1.7%	14 2.5%
1-5 years ago	1144 13.1%	90 25.8%	125 13.7%	124 22.1%	1482 14.1%
Between 5-10 years ago	1618 18.6%	77 22.3%	187 20.5%	113 20.3%	1996 18.9%
More than 10 years ago	5787 66.4%	164 47.2%	587 64.1%	307 55.0%	6845 64.9%
I don't know	15 0.2%	2 0.5%	1 0.1%	1 0.1%	18 0.2%
Total	8721 100.0%	347 100.0%	915 100.0%	558 100.0%	10542 100.0%

## Access to disease modifying therapies (DMTs)

Table 6 - Use of DMTs among those who could potentially benefit<sup>6</sup>

	Nation				UK
	England	Northern Ireland	Scotland	Wales	
Not taking a DMT	2209 44.4%	62 23.3%	230 42.8%	162 51.2%	2664 43.7%
Taking a DMT	2765 55.6%	206 76.7%	308 57.2%	154 48.8%	3433 56.3%
Total	4974 100.0%	268 100.0%	538 100.0%	316 100.0%	6097 100.0%

<sup>6</sup> People who 'could potentially benefit' are considered to be those that stated they have a relapsing form of MS, or who have listed that they are taking a DMT

Table 7 - Use of DMTs by combination of access to MS nurses, neurologists or information about drugs

	England			Northern Ireland			Scotland			Wales			UK		
	Not taking DMT	Taking DMT	Total	Not taking DMT	Taking DMT	Total	Not taking DMT	Taking DMT	Total	Not taking DMT	Taking DMT	Total	Not taking DMT	Taking DMT	Total
Access to no 'services'	432 90.0%	48 10.0%	480 100.0%	10 66.7%	5 33.3%	15 100.0%	66 86.8%	10 13.2%	76 100.0%	24 80.0%	6 20.0%	30 100.0%	532 88.7%	68 11.3%	600 100.0%
Access to one 'service'	668 69.7%	290 30.3%	958 100.0%	20 42.6%	27 57.4%	47 100.0%	73 75.3%	24 24.7%	97 100.0%	66 85.7%	11 14.3%	77 100.0%	827 70.2%	351 29.8%	1178 100.0%
Access to two 'services'	732 42.0%	1009 58.0%	1741 100.0%	21 18.9%	90 81.1%	111 100.0%	63 37.1%	107 62.9%	170 100.0%	51 50.0%	51 50.0%	102 100.0%	867 40.8%	1257 59.2%	2124 100.0%
Access to three 'services'	327 19.2%	1377 80.8%	1704 100.0%	8 8.8%	83 91.2%	91 100.0%	25 13.3%	163 86.7%	188 100.0%	20 18.7%	87 81.3%	107 100.0%	380 18.2%	1710 81.8%	2090 100.0%
Estimated could potentially benefit from DMTs	2159 44.2%	2724 55.8%	4883 100.0%	59 22.3%	205 77.7%	264 100.0%	227 42.7%	304 57.3%	531 100.0%	161 50.9%	155 49.1%	316 100.0%	2606 43.5%	3386 56.5%	5992 100.0%

Table 8 - Use of DMTs by access to information about drugs

	England			Northern Ireland			Scotland			Wales			UK			
	Not taking DMT	Taking DMT	Total	Not taking DMT	Taking DMT	Total	Not taking DMT	Taking DMT	Total	Not taking DMT	Taking DMT	Total	Not taking DMT	Taking DMT	Total	
<b>Have you received enough information from your health professionals about drugs available to support the treatment of your MS?</b>	Yes, I have been provided with enough information	589 27.3%	1660 60.9%	2249 46.1%	20 33.9%	109 53.4%	129 49.0%	55 24.1%	191 63.0%	246 46.3%	44 27.3%	93 60.0%	137 43.4%	708 27.2%	2054 60.6%	2762 46.1%
	No, I have not been provided with enough information	664 30.8%	460 16.9%	1124 23.0%	20 33.9%	49 24.0%	69 26.2%	71 31.1%	53 17.5%	124 23.4%	62 38.5%	40 25.8%	102 32.3%	816 31.3%	602 17.8%	1418 23.7%
	No, I have not sought this information from health professionals	906 42.0%	604 22.2%	1510 30.9%	19 32.2%	46 22.5%	65 24.7%	102 44.7%	59 19.5%	161 30.3%	55 34.2%	22 14.2%	77 24.4%	1082 41.5%	731 21.6%	1813 30.3%
	Total	2159 100.0%	2724 100.0%	4883 100.0%	59 100.0%	204 100.0%	263 100.0%	228 100.0%	303 100.0%	531 100.0%	161 100.0%	155 100.0%	316 100.0%	2606 100.0%	3387 100.0%	5993 100.0%

Table 9 - Use of DMTs by access to MS specialist nurse

	England			Northern Ireland			Scotland			Wales			UK			
	Not taking DMT	Taking DMT	Total	Not taking DMT	Taking DMT	Total	Not taking DMT	Taking DMT	Total	Not taking DMT	Taking DMT	Total	Not taking DMT	Taking DMT	Total	
<b>In the past 12 months, have you seen an MS specialist nurse in relation to your MS?</b>	Yes	1298 59.3%	2427 88.6%	3725 75.6%	27 43.5%	161 79.7%	188 71.2%	112 49.3%	291 95.7%	403 75.9%	127 79.9%	145 94.2%	272 86.9%	1565 59.3%	3024 89.0%	4589 76.0%
	No, and I have not needed to	565 25.8%	193 7.0%	758 15.4%	23 37.1%	22 10.9%	45 17.0%	74 32.6%	5 1.6%	79 14.9%	14 8.8%	3 1.9%	17 5.4%	676 25.6%	224 6.6%	900 14.9%
	No, but I needed to	299 13.7%	103 3.8%	402 8.2%	12 19.4%	18 8.9%	30 11.4%	37 16.3%	8 2.6%	45 8.5%	18 11.3%	6 3.9%	24 7.7%	365 13.8%	134 3.9%	499 8.3%
	I am not sure	28 1.3%	15 0.5%	43 0.9%	0 0.0%	1 0.5%	1 0.4%	4 1.8%	0 0.0%	4 0.8%	0 0.0%	0 0.0%	0 0.0%	32 1.2%	17 0.5%	49 0.8%
	Total	2190 100.0%	2738 100.0%	4928 100.0%	62 100.0%	202 100.0%	264 100.0%	227 100.0%	304 100.0%	531 100.0%	159 100.0%	154 100.0%	313 100.0%	2638 100.0%	3399 100.0%	6037 100.0%

Table 10 - Use of DMTs by access to MS neurologists

	England			Northern Ireland			Scotland			Wales			UK			
	Not taking DMT	Taking DMT	Total	Not taking DMT	Taking DMT	Total	Not taking DMT	Taking DMT	Total	Not taking DMT	Taking DMT	Total	Not taking DMT	Taking DMT	Total	
<b>In the past 12 months, have you seen a neurologist in relation to your MS?</b>	Yes	1274 58.3%	2423 88.5%	3697 75.1%	42 66.7%	186 91.6%	228 85.7%	113 49.8%	250 81.7%	363 68.1%	57 36.1%	137 88.4%	194 62.0%	1486 56.4%	2997 88.0%	4483 74.2%
	No, and I have not needed to	630 28.8%	188 6.9%	818 16.6%	8 12.7%	6 3.0%	14 5.3%	82 36.1%	37 12.1%	119 22.3%	71 44.9%	7 4.5%	78 24.9%	791 30.0%	239 7.0%	1030 17.1%
	No, but I needed to	259 11.8%	114 4.2%	373 7.6%	13 20.6%	10 4.9%	23 8.6%	29 12.8%	13 4.2%	42 7.9%	29 18.4%	10 6.5%	39 12.5%	330 12.5%	147 4.3%	477 7.9%
	I am not sure	23 1.1%	13 0.5%	36 0.7%	0 0.0%	1 0.5%	1 0.4%	3 1.3%	6 2.0%	9 1.7%	1 0.6%	1 0.6%	2 0.6%	27 1.0%	21 0.6%	48 0.8%
	Total	2186 100.0%	2738 100.0%	4924 100.0%	63 100.0%	203 100.0%	266 100.0%	227 100.0%	306 100.0%	533 100.0%	158 100.0%	155 100.0%	313 100.0%	2634 100.0%	3404 100.0%	6038 100.0%

Table 11 - Use of DMTs by time since diagnosis

	England			Northern Ireland			Scotland			Wales			UK		
	Not taking a DMT	Taking a DMT	Total	Not taking a DMT	Taking a DMT	Total	Not taking a DMT	Taking a DMT	Total	Not taking a DMT	Taking a DMT	Total	Not taking a DMT	Taking a DMT	Total
Less than 12 months ago	35 26.3%	98 73.7%	133 100.0%	4 26.7%	11 73.3%	15 100.0%	1 7.1%	13 92.9%	14 100.0%	6 66.7%	3 33.3%	9 100.0%	45 26.3%	126 73.7%	171 100.0%
1-5 years ago	214 24.5%	661 75.5%	875 100.0%	9 11.7%	68 88.3%	77 100.0%	23 22.8%	78 77.2%	101 100.0%	32 34.4%	61 65.6%	93 100.0%	278 24.3%	868 75.7%	1146 100.0%
Between 5-10 years ago	372 34.1%	719 65.9%	1091 100.0%	13 20.6%	50 79.4%	63 100.0%	33 25.4%	97 74.6%	130 100.0%	33 45.2%	40 54.8%	73 100.0%	451 33.3%	905 66.7%	1356 100.0%
More than 10 years ago	1520 55.8%	1205 44.2%	2725 100.0%	33 33.3%	66 66.7%	99 100.0%	169 59.3%	116 40.7%	285 100.0%	89 64.0%	50 36.0%	139 100.0%	1810 55.7%	1438 44.3%	3248 100.0%
I don't know	4 57.1%	3 42.9%	7 100.0%	0 0.0%	1 100.0%	1 100.0%	0 0.0%	0 0.0%	0 0.0%	1 100.0%	0 0.0%	1 100.0%	5 55.6%	4 44.4%	9 100.0%
Total	2145 44.4%	2686 55.6%	4831 100.0%	59 23.1%	196 76.9%	255 100.0%	226 42.6%	304 57.4%	530 100.0%	161 51.1%	154 48.9%	315 100.0%	2589 43.7%	3341 56.3%	5930 100.0%

Table 12 - Use of specific DMTs by nation

	Nation				UK
	England	Northern Ireland	Scotland	Wales	
Taking Aubagio	45 0.9%	4 1.4%	1 0.2%	0 0.0%	50 0.8%
Taking Avonex	301 6.1%	27 10.0%	31 5.7%	7 2.3%	366 6.0%
Taking Betaferon	159 3.2%	5 1.9%	11 2.0%	6 1.7%	180 3.0%
Taking Copaxone	384 7.7%	29 11.0%	60 11.2%	18 5.8%	492 8.1%
Taking Extavia	2 0.0%	0 0.0%	11 2.1%	0 0.0%	13 0.2%
Taking Gilenya	419 8.4%	7 2.5%	35 6.6%	18 5.7%	479 7.9%
Taking Lemtrada	95 1.9%	6 2.1%	3 0.6%	16 5.1%	120 2.0%
Taking Plegridy	35 0.7%	4 1.4%	15 2.8%	5 1.7%	59 1.0%
Taking Rebif	291 5.8%	24 9.0%	19 3.6%	11 3.5%	345 5.7%
Taking Tecfidera	603 12.1%	74 27.7%	91 16.9%	46 14.5%	814 13.4%
Taking Tysabri	430 8.6%	26 9.9%	31 5.7%	27 8.4%	514 8.4%
Not taking any DMTs	2209 44.4%	62 23.3%	230 42.8%	162 51.2%	2664 43.7%
Total	4974 100.0%	268 100.0%	538 100.0%	316 100.0%	6097 100.0%

Table 13 - Use of DMTs by access to both MS nurse and neurologist

	Not seen MS nurse or neurologist in past 12 months	Seen both MS nurse and neurologist in past 12 months
Not taking a DMT	570 88.3%	995 27.0%
Taking a DMT	76 11.7%	2685 73.0%
Total	645 100.0%	3680 100.0%

## Access to symptom management therapies

Table 14 - Use of symptom management therapies<sup>7</sup>

	Nation				UK
	England	Northern Ireland	Scotland	Wales	
Taking any of the symptom management drugs below	712 8.4%	16 4.8%	56 6.4%	24 4.4%	808 7.9%
Taking Sativex	127 1.5%	3 0.8%	19 2.1%	6 1.1%	154 1.5%
Taking Fampyra	114 1.3%	7 2.1%	9 1.0%	5 1.0%	135 1.3%
Taking Botox	495 5.9%	7 2.0%	35 3.9%	14 2.6%	550 5.4%
Total	8440 100.0%	335 100.0%	887 100.0%	535 100.0%	10197 100.0%

## Need and access to services and support

### MS nurses

Table 15 - Need and access to an MS specialist nurse

	Nation				UK	
	England	Northern Ireland	Scotland	Wales		
<b>In the past 12 months, have you seen an MS specialist nurse in relation to your MS?</b>	Yes	6033 67.9%	236 66.3%	602 65.2%	451 80.8%	7320 68.3%
	No, and I have not needed to	1779 20.0%	73 20.6%	201 21.8%	43 7.7%	2096 19.5%
	No, but I needed to	974 11.0%	43 12.0%	110 11.9%	59 10.6%	1186 11.1%
	I am not sure	100 1.1%	4 1.1%	11 1.2%	5 0.9%	120 1.1%
	Total	8885 100.0%	355 100.0%	923 100.0%	558 100.0%	10721 100.0%
	Total need	78.9%	78.4%	77.0%	91.4%	79.3%
	Need met	86.1%	84.7%	84.6%	88.4%	86.1%

<sup>7</sup> Note that respondents could be taking multiple symptom management drugs

Table 16 - Contact method for those who responded yes to having seen an MS specialist nurse<sup>8</sup>

	Nation				UK
	England	Northern Ireland	Scotland	Wales	
In a specialist clinic in a hospital setting	4363 72.3%	204 86.4%	483 80.2%	391 86.7%	5440 74.3%
In an outreach clinic in a community setting	782 13.0%	6 2.5%	61 10.2%	35 7.8%	884 12.1%
In your home	1062 17.6%	14 6.0%	56 9.4%	47 10.5%	1180 16.1%
By telephone	1254 20.8%	76 32.2%	132 22.0%	129 28.5%	1591 21.7%
By email	448 7.4%	37 15.8%	55 9.1%	14 3.2%	554 7.6%
Total	6033 100.0%	236 100.0%	602 100.0%	451 100.0%	7320 100.0%

Table 17 - Access to an MS nurse by time since diagnosis (UK)

UK	Time since diagnosis					Total
	Less than 12 months ago	1-5 years ago	Between 5-10 years ago	More than 10 years ago	I don't know	
Yes	174 88.3%	1236 84.3%	1513 76.4%	4161 61.8%	12 70.6%	7096 68.3%
No, and I have not needed to	9 4.6%	125 8.5%	289 14.6%	1608 23.9%	0 0.0%	2031 19.6%
No, but I needed to	14 7.1%	97 6.6%	167 8.4%	868 12.9%	3 17.6%	1149 11.1%
I am not sure	0 0.0%	8 0.5%	11 0.6%	91 1.4%	2 11.8%	112 1.1%
Total	197 100.0%	1466 100.0%	1980 100.0%	6728 100.0%	17 100.0%	10388 100.0%
Total need MS nurse	95.4%	90.9%	84.8%	74.7%	88.2%	
Need met MS nurse	92.6%	92.7%	90.1%	82.7%	80.0%	

<sup>8</sup> Percentages will sum to greater than 100% as multiple answers were possible

Table 18 - Access to an MS nurse by time since diagnosis (England)

England		Time since diagnosis					Total
		Less than 12 months ago	1-5 years ago	Between 5-10 years ago	More than 10 years ago	I don't know	
In the past 12 months, have you seen an MS specialist nurse in relation to your MS?	Yes	136 88.9%	958 84.6%	1233 76.7%	3509 61.6%	10 66.7%	5846 67.9%
	No, and I have not needed to	9 5.9%	96 8.5%	243 15.1%	1378 24.2%	0 0.0%	1726 20.1%
	No, but I needed to	8 5.2%	73 6.4%	124 7.7%	734 12.9%	3 20.0%	942 10.9%
	I am not sure	0 0.0%	6 0.5%	8 0.5%	76 1.3%	2 13.3%	92 1.1%
	Total	153 100.0%	1133 100.0%	1608 100.0%	5697 100.0%	15 100.0%	8606 100.0%
	Total need MS nurse	94.1%	91.0%	84.4%	74.5%	86.7%	
	Need met MS nurse	94.4%	92.9%	90.9%	82.7%	76.9%	

Table 19 - Access to an MS nurse by time since diagnosis (Northern Ireland)

Northern Ireland		Time since diagnosis					Total
		Less than 12 months ago	1-5 years ago	Between 5-10 years ago	More than 10 years ago	I don't know	
In the past 12 months, have you seen an MS specialist nurse in relation to your MS?	Yes	13 92.9%	61 70.1%	56 73.7%	93 59.2%	1 100.0%	224 66.9%
	No, and I have not needed to	0 0.0%	16 18.4%	11 14.5%	41 26.1%	0 0.0%	68 20.3%
	No, but I needed to	1 7.1%	9 10.3%	8 10.5%	22 14.0%	0 0.0%	40 11.9%
	I am not sure	0 0.0%	1 1.1%	1 1.3%	1 0.6%	0 0.0%	3 0.9%
	Total	14 100.0%	87 100.0%	76 100.0%	157 100.0%	1 100.0%	335 100.0%
	Total need MS nurse	100.0%	80.5%	84.2%	73.2%	100.0%	
	Need met MS nurse	92.9%	87.1%	87.5%	80.9%	100.0%	

Table 20 - Access to an MS nurse by time since diagnosis (Scotland)

Scotland		Time since diagnosis					Total
		Less than 12 months ago	1-5 years ago	Between 5-10 years ago	More than 10 years ago	I don't know	
In the past 12 months, have you seen an MS specialist nurse in relation to your MS?	Yes	15 93.8%	106 87.6%	132 70.6%	334 58.0%	1 100.0%	588 65.3%
	No, and I have not needed to	0 0.0%	10 8.3%	31 16.6%	154 26.7%	0 0.0%	195 21.6%
	No, but I needed to	1 6.3%	5 4.1%	24 12.8%	77 13.4%	0 0.0%	107 11.9%
	I am not sure	0 0.0%	0 0.0%	0 0.0%	11 1.9%	0 0.0%	11 1.2%
	Total	16 100.0%	121 100.0%	187 100.0%	576 100.0%	1 100.0%	901 100.0%
	Total need MS nurse	100.0%	91.7%	83.4%	71.4%	100.0%	
	Need met MS nurse	93.8%	95.5%	84.6%	81.3%	100.0%	

Table 21 - Access to an MS nurse by time since diagnosis (Wales)

Wales		Time since diagnosis					Total
		Less than 12 months ago	1-5 years ago	Between 5-10 years ago	More than 10 years ago	I don't know	
In the past 12 months, have you seen an MS specialist nurse in relation to your MS?	Yes	11 78.6%	111 89.5%	92 86.0%	225 75.8%	1 100.0%	440 81.0%
	No, and I have not needed to	0 0.0%	3 2.4%	3 2.8%	34 11.4%	0 0.0%	40 7.4%
	No, but I needed to	3 21.4%	10 8.1%	11 10.3%	35 11.8%	0 0.0%	59 10.9%
	I am not sure	0 0.0%	0 0.0%	1 0.9%	3 1.0%	0 0.0%	4 0.7%
	Total	14 100.0%	124 100.0%	107 100.0%	297 100.0%	1 100.0%	543 100.0%
	Total need MS nurse	100.0%	97.6%	96.3%	87.5%	100%	
	Need met MS nurse	78.6%	91.7%	89.3%	86.5%	100%	

## Neurologists

Table 22 - Need and access to a neurologist

		Nation				UK
		England	Northern Ireland	Scotland	Wales	
<b>In the past 12 months, have you seen a neurologist in relation to your MS?</b>	Yes	5671 64.0%	294 81.7%	522 56.4%	285 50.9%	6771 63.2%
	No, and I have not needed to	2183 24.6%	26 7.4%	289 31.2%	174 31.1%	2672 25.0%
	No, but I needed to	897 10.1%	35 9.8%	94 10.2%	95 16.9%	1122 10.5%
	I am not sure	114 1.3%	4 1.1%	20 2.2%	6 1.1%	144 1.3%
	Total	8864 100.0%	360 100.0%	925 100.0%	560 100.0%	10709 100.0%
	Total need	74.1%	91.5%	66.6%	67.8%	73.7%
	Need met	86.3%	89.2%	84.7%	75.1%	85.7%

Table 23 - Access to a neurologist by time since diagnosis (UK)

UK		Time since diagnosis					Total
		Less than 12 months ago	1-5 years ago	Between 5-10 years ago	More than 10 years ago	I don't know	
In the past 12 months, have you seen a neurologist in relation to your MS?	Yes	193 96.5%	1206 82.3%	1417 71.9%	3744 55.7%	9 50.0%	6569 63.3%
	No, and I have not needed to	6 3.0%	159 10.8%	359 18.2%	2071 30.8%	5 27.8%	2600 25.0%
	No, but I needed to	1 0.5%	90 6.1%	176 8.9%	805 12.0%	3 16.7%	1075 10.4%
	I am not sure	0 0.0%	11 0.8%	20 1.0%	105 1.6%	1 5.6%	137 1.3%
	Total	200 100.0%	1466 100.0%	1972 100.0%	6725 100.0%	18 100.0%	10381 100.0%
	Total need Neurologist	97.0%	88.4%	80.8%	67.6%	66.7%	
	Need met neurologist	99.5%	93.1%	89.0%	82.3%	75.0%	

Table 24 - Access to a neurologist by time since diagnosis (England)

England		Time since diagnosis					Total
		Less than 12 months ago	1-5 years ago	Between 5-10 years ago	More than 10 years ago	I don't know	
In the past 12 months, have you seen a neurologist in relation to your MS?	Yes	151 97.4%	943 83.2%	1190 74.4%	3207 56.4%	7 46.7%	5498 64.0%
	No, and I have not needed to	3 1.9%	111 9.8%	272 17.0%	1737 30.5%	4 26.7%	2127 24.8%
	No, but I needed to	1 0.6%	70 6.2%	122 7.6%	663 11.6%	3 20.0%	859 10.0%
	I am not sure	0 0.0%	9 0.8%	15 0.9%	84 1.5%	1 6.7%	109 1.3%
	Total	155 100.0%	1133 100.0%	1599 100.0%	5691 100.0%	15 100.0%	8593 100.0%
	Total need neurologist	98.1%	89.4%	82.1%	68.0%	66.7%	
	Need met neurologist	99.3%	93.1%	90.7%	82.9%	70.0%	

Table 25 - Access to a neurologist by time since diagnosis (Northern Ireland)

Northern Ireland		Time since diagnosis					Total
		Less than 12 months ago	1-5 years ago	Between 5-10 years ago	More than 10 years ago	I don't know	
In the past 12 months, have you seen a neurologist in relation to your MS?	Yes	15 100.0%	81 92.0%	58 75.3%	125 78.6%	2 100.0%	281 82.4%
	No, and I have not needed to	0 0.0%	4 4.5%	8 10.4%	13 8.2%	0 0.0%	25 7.3%
	No, but I needed to	0 0.0%	3 3.4%	10 13.0%	18 11.3%	0 0.0%	31 9.1%
	I am not sure	0 0.0%	0 0.0%	1 1.3%	3 1.9%	0 0.0%	4 1.2%
	Total	15 100.0%	88 100.0%	77 100.0%	159 100.0%	2 100.0%	341 100.0%
	Total need neurologist	100.0%	95.5%	88.3%	89.9%	100.0%	
	Need met neurologist	100.0%	96.4%	85.3%	87.4%	100.0%	

Table 26 - Access to a neurologist by time since diagnosis (Scotland)

Scotland		Time since diagnosis					Total
		Less than 12 months ago	1-5 years ago	Between 5-10 years ago	More than 10 years ago	I don't know	
In the past 12 months, have you seen a neurologist in relation to your MS?	Yes	14 93.3%	103 82.4%	116 62.4%	280 48.8%	0 0.0%	513 56.9%
	No, and I have not needed to	1 6.7%	17 13.6%	49 26.3%	211 36.8%	0 0.0%	278 30.9%
	No, but I needed to	0 0.0%	4 3.2%	18 9.7%	69 12.0%	0 0.0%	91 10.1%
	I am not sure	0 0.0%	1 0.8%	3 1.6%	14 2.4%	1 100.0%	19 2.1%
	Total	15 100.0%	125 100.0%	186 100.0%	574 100.0%	1 100.0%	901 100.0%
	Total need neurologist	93.3%	85.6%	72.0%	60.8%	0.0%	
	Need met neurologist	100.0%	96.3%	86.6%	80.2%	0.0%	

Table 27 - Access to a neurologist by time since diagnosis (Wales)

Wales		Time since diagnosis					Total
		Less than 12 months ago	1-5 years ago	Between 5-10 years ago	More than 10 years ago	I don't know	
In the past 12 months, have you seen a neurologist in relation to your MS?	Yes	12 92.3%	79 65.8%	53 48.6%	132 43.9%	0 0.0%	276 50.7%
	No, and I have not needed to	1 7.7%	27 22.5%	30 27.5%	110 36.5%	1 100.0%	169 31.1%
	No, but I needed to	0 0.0%	13 10.8%	25 22.9%	55 18.3%	0 0.0%	93 17.1%
	I am not sure	0 0.0%	1 0.8%	1 0.9%	4 1.3%	0 0.0%	6 1.1%
	Total	13 100.0%	120 100.0%	109 100.0%	301 100.0%	1 100.0%	544 100.0%
	Total need neurologist	92.3%	76.7%	71.6%	62.1%	0.0%	
	Need met neurologist	100.0%	85.9%	67.9%	70.6%	0.0%	

### Specialists about continence advice

Table 28 - Need and access to a specialist about continence advice

		Nation				UK
		England	Northern Ireland	Scotland	Wales	
In the past 12 months, have you seen a specialist about continence advice in relation to your MS?	Yes	3179 36.0%	135 37.6%	279 30.5%	241 42.9%	3834 36.0%
	No, and I have not needed support	4356 49.4%	170 47.4%	494 53.9%	236 42.0%	5256 49.3%
	No, but I needed support	1156 13.1%	50 13.9%	131 14.3%	80 14.1%	1417 13.3%
	I am not sure	132 1.5%	4 1.1%	11 1.3%	5 1.0%	152 1.4%
	Total	8823 100.0%	358 100.0%	916 100.0%	562 100.0%	10659 100.0%
	Total need	49.1%	51.6%	44.8%	57.1%	49.3%
	Need met	73.3%	73.0%	68.0%	75.2%	73.0%

Table 29 - Access to a specialist about continence advice by time since diagnosis (UK)

		Time since diagnosis					Total
		Less than 12 months ago	1-5 years ago	Between 5-10 years ago	More than 10 years ago	I don't know	
<b>In the past 12 months, have you seen a specialist about continence advice in relation to your MS?</b>	Yes	49 24.6%	421 28.8%	646 33.0%	2579 38.5%	7 38.9%	3702 35.8%
	No, and I have not needed support	116 58.3%	835 57.1%	1026 52.4%	3145 47.0%	4 22.2%	5126 49.6%
	No, but I needed support	30 15.1%	194 13.3%	257 13.1%	877 13.1%	7 38.9%	1365 13.2%
	I am not sure	4 2.0%	12 0.8%	30 1.5%	97 1.4%	0 0.0%	143 1.4%
	Total	199 100.0%	1462 100.0%	1959 100.0%	6698 100.0%	18 100.0%	10336 100.0%
	Total need continence advice	39.7%	42.1%	46.1%	51.6%	77.8%	
	Need met continence advice	62.0%	68.5%	71.5%	74.6%	50.0%	

Table 30 - Access to a specialist about continence advice by time since diagnosis (England)

England		Time since diagnosis					Total
		Less than 12 months ago	1-5 years ago	Between 5-10 years ago	More than 10 years ago	I don't know	
In the past 12 months, have you seen a specialist about continence advice in relation to your MS?	Yes	35 22.6%	336 29.7%	525 33.0%	2166 38.2%	5 33.3%	3067 35.8%
	No, and I have not needed support	94 60.6%	640 56.6%	841 52.9%	2674 47.2%	3 20.0%	4252 49.7%
	No, but I needed support	22 14.2%	145 12.8%	201 12.6%	739 13.0%	7 46.7%	1114 13.0%
	I am not sure	4 2.6%	9 0.8%	23 1.4%	87 1.5%	0 0.0%	123 1.4%
	Total	155 100.0%	1130 100.0%	1590 100.0%	5666 100.0%	15 100.0%	8556 100.0%
	Total need continence advice	36.8%	42.6%	45.7%	51.3%	80.0%	
	Need met continence advice	61.4%	69.9%	72.3%	74.6%	41.7%	

Table 31 - Access to a specialist about continence advice by time since diagnosis (Northern Ireland)

Northern Ireland		Time since diagnosis					Total
		Less than 12 months ago	1-5 years ago	Between 5-10 years ago	More than 10 years ago	I don't know	
In the past 12 months, have you seen a specialist about continence advice in relation to your MS?	Yes	8 53.3%	29 32.2%	27 36.0%	64 40.5%	2 100.0%	130 38.2%
	No, and I have not needed support	6 40.0%	46 51.1%	40 53.3%	69 43.7%	0 0.0%	161 47.4%
	No, but I needed support	1 6.7%	14 15.6%	7 9.3%	23 14.6%	0 0.0%	45 13.2%
	I am not sure	0 0.0%	1 1.1%	1 1.3%	2 1.3%	0 0.0%	4 1.2%
	Total	15 100.0%	90 100.0%	75 100.0%	158 100.0%	2 100.0%	340 100.0%
	Total need continence advice	60.0%	47.8%	45.3%	55.1%	100.0%	
	Need met continence advice	88.9%	67.4%	79.4%	73.6%	100.0%	

Table 32 - Access to a specialist about continence advice by time since diagnosis (Scotland)

Scotland		Time since diagnosis					Total
		Less than 12 months ago	1-5 years ago	Between 5-10 years ago	More than 10 years ago	I don't know	
In the past 12 months, have you seen a specialist about continence advice in relation to your MS?	Yes	5 31.3%	16 13.4%	49 26.3%	201 35.3%	0 0.0%	271 30.4%
	No, and I have not needed support	9 56.3%	79 66.4%	104 55.9%	289 50.8%	1 100.0%	482 54.1%
	No, but I needed support	2 12.5%	23 19.3%	30 16.1%	74 13.0%	0 0.0%	129 14.5%
	I am not sure	0 0.0%	1 0.8%	3 1.6%	5 0.9%	0 0.0%	9 1.0%
	Total	16 100.0%	119 100.0%	186 100.0%	569 100.0%	1 100.0%	891 100.0%
	Total need continence advice	43.8%	32.8%	42.5%	48.3%	0.0%	
	Need met continence advice	71.4%	41.0%	62.0%	73.1%	0.0%	

Table 33 - Access to a specialist about continence advice by time since diagnosis (Wales)

Wales		Time since diagnosis					Total
		Less than 12 months ago	1-5 years ago	Between 5-10 years ago	More than 10 years ago	I don't know	
In the past 12 months, have you seen a specialist about continence advice in relation to your MS?	Yes	1 7.7%	40 32.5%	45 41.7%	147 48.7%	1 100.0%	234 42.8%
	No, and I have not needed support	7 53.8%	70 56.9%	41 38.0%	112 37.1%	0 0.0%	230 42.0%
	No, but I needed support	5 38.5%	13 10.6%	19 17.6%	41 13.6%	0 0.0%	78 14.3%
	I am not sure	0 0.0%	0 0.0%	3 2.8%	2 0.7%	0 0.0%	5 0.9%
	Total	13 100.0%	123 100.0%	108 100.0%	302 100.0%	1 100.0%	547 100.0%
	Total need continence advice	46.2%	43.1%	59.3%	62.3%	100.0%	
	Need met continence advice	16.7%	75.5%	70.3%	78.2%	100.0%	

## Physical activity

Table 34 - Access to support to keep physically active

		Nation				UK
		England	Northern Ireland	Scotland	Wales	
<b>Have you received support so that you can keep physically active?</b>	Yes, from the NHS	709 8.1%	36 10.1%	70 7.7%	63 11.4%	878 8.3%
	Yes, from my local council (or Trust in Northern Ireland)	202 2.3%	21 5.9%	47 5.1%	40 7.2%	309 2.9%
	Yes, from a charity or voluntary organisation	957 10.9%	37 10.4%	62 6.8%	35 6.3%	1091 10.3%
	Yes, from somewhere else	850 9.7%	37 10.7%	88 9.6%	39 7.1%	1015 9.6%
	No, and I have not needed to	3737 42.7%	129 36.8%	426 46.7%	212 38.4%	4505 42.6%
	No, but I needed to	2241 25.6%	90 25.5%	208 22.8%	161 29.1%	2700 25.6%
	I am not sure	303 3.5%	17 4.8%	32 3.5%	22 3.9%	374 3.5%
	Total <sup>9</sup>	9000 102.8%	366 104.3%	933 102.2%	572 103.5%	10871 102.9%
	Percentage of respondents who received support	28.2%	32.9%	27.0%	28.6%	28.3%

<sup>9</sup> Percentages will sum to greater than 100% as multiple answers were possible

## Physiotherapy

Table 35 - Access to a physiotherapist

		Nation				UK
		England	Northern Ireland	Scotland	Wales	
<b>In the past 12 months, have you seen a physiotherapist in relation to your MS?</b>	Yes, from the NHS	2745 31.1%	144 40.4%	274 29.8%	221 39.7%	3384 31.7%
	Yes, privately	615 7.0%	23 6.4%	58 6.3%	27 4.9%	724 6.8%
	Yes, from a charity or voluntary organisation	600 6.8%	31 8.8%	57 6.1%	26 4.6%	713 6.7%
	Yes, from somewhere else	108 1.2%	4 1.1%	13 1.4%	6 1.1%	131 1.2%
	No, and I have not needed to	3431 38.9%	109 30.6%	386 41.8%	176 31.6%	4101 38.5%
	No, but I needed to	1454 16.5%	62 17.4%	155 16.8%	100 18.1%	1772 16.6%
	I am not sure	182 2.1%	3 0.7%	13 1.4%	13 2.3%	210 2.0%
	Total <sup>10</sup>	9135 103.5%	376 105.4%	955 103.7%	569 102.4%	11035 103.5%
	Percentage of respondents who received support	42.6%	51.3%	40.0%	48.0%	42.9%

10 Percentages will sum to greater than 100% as multiple answers were possible

Table 36 - Access to a physiotherapist by time since diagnosis (UK)<sup>11</sup>

UK		Time since diagnosis					Total
		Less than 12 months ago	1-5 years ago	Between 5-10 years ago	More than 10 years ago	I don't know	
<b>In the past 12 months, have you seen a physiotherapist in relation to your MS?</b>	Yes, from the NHS	69 34.7%	455 31.2%	593 30.1%	2138 31.9%	9 52.4%	3265
	Yes, privately	8 4.2%	76 5.2%	122 6.2%	498 7.4%	1 5.5%	705
	Yes, from a charity or voluntary organisation	6 2.8%	57 3.9%	111 5.6%	522 7.8%	0 0.0%	696
	Yes, from somewhere else	2 1.2%	16 1.1%	16 0.8%	91 1.4%	0 0.0%	125
	No, and I have not needed to	84 41.8%	673 46.1%	838 42.6%	2392 35.7%	7 38.2%	3993
	No, but I needed to	34 16.9%	202 13.8%	297 15.1%	1184 17.7%	1 4.0%	1717
	I am not sure	0 0.0%	21 1.4%	43 2.2%	136 2.0%	1 4.1%	201
	Total	200	1460	1968	6693	18	10339

<sup>11</sup> Note respondents could select all that applied

Table 37 - Access to a physiotherapist by time since diagnosis (England)<sup>12</sup>

England		Time since diagnosis					Total
		Less than 12 months ago	1-5 years ago	Between 5-10 years ago	More than 10 years ago	I don't know	
<b>In the past 12 months, have you seen a physiotherapist in relation to your MS?</b>	Yes, from the NHS	60 38.5%	332 29.6%	469 29.3%	1779 31.4%	7 49.1%	2647
	Yes, privately	7 4.8%	63 5.6%	107 6.7%	421 7.4%	0 0.0%	599
	Yes, from a charity or voluntary organisation	2 1.4%	30 2.7%	102 6.3%	453 8.0%	0 0.0%	587
	Yes, from somewhere else	1 0.6%	12 1.1%	12 0.7%	78 1.4%	0 0.0%	103
	No, and I have not needed to	67 42.6%	540 48.0%	685 42.8%	2041 36.0%	7 46.1%	3340
	No, but I needed to	22 14.1%	158 14.0%	233 14.5%	998 17.6%	1 4.8%	1411
	I am not sure	0 0.0%	16 1.5%	39 2.4%	116 2.1%	1 5.0%	173
	Total	156	1123	1602	5663	15	8559

<sup>12</sup> Note respondents could select all that applied

Table 38 - Access to a physiotherapist by time since diagnosis (Northern Ireland)<sup>13</sup>

Northern Ireland		Time since diagnosis					Total
		Less than 12 months ago	1-5 years ago	Between 5-10 years ago	More than 10 years ago	I don't know	
<b>In the past 12 months, have you seen a physiotherapist in relation to your MS?</b>	Yes, from the NHS	0 0.0%	37 41.3%	38 50.3%	58 36.9%	1 40.5%	133
	Yes, privately	1 6.6%	4 4.2%	4 4.7%	14 8.6%	1 59.5%	23
	Yes, from a charity or voluntary organisation	1 9.3%	12 12.8%	3 3.7%	12 7.9%	0 0.0%	28
	Yes, from somewhere else	0 0.0%	0 0.0%	1 1.3%	2 1.1%	0 0.0%	3
	No, and I have not needed to	4 30.4%	27 30.6%	27 36.1%	46 29.4%	0 0.0%	105
	No, but I needed to	8 53.7%	14 15.8%	5 7.1%	32 20.3%	0 0.0%	59
	I am not sure	0 0.0%	0 0.0%	0 0.0%	3 1.6%	0 0.0%	3
	<b>Total</b>	<b>15</b>	<b>90</b>	<b>75</b>	<b>157</b>	<b>2</b>	<b>338</b>

<sup>13</sup> Note respondents could select all that applied

Table 39 - Access to a physiotherapist by time since diagnosis (Scotland)<sup>14</sup>

Scotland		Time since diagnosis					Total
		Less than 12 months ago	1-5 years ago	Between 5-10 years ago	More than 10 years ago	I don't know	
<b>In the past 12 months, have you seen a physiotherapist in relation to your MS?</b>	Yes, from the NHS	6 35.6%	33 26.7%	48 26.1%	181 31.4%	1 100.0%	268
	Yes, privately	0 0.0%	4 3.6%	8 4.1%	45 7.8%	0 0.0%	57
	Yes, from a charity or voluntary organisation	2 13.6%	9 7.1%	3 1.9%	41 7.1%	0 0.0%	55
	Yes, from somewhere else	0 0.0%	4 3.3%	3 1.5%	6 1.0%	0 0.0%	13
	No, and I have not needed to	7 44.6%	63 51.0%	88 48.1%	219 38.1%	0 0.0%	377
	No, but I needed to	1 6.3%	17 13.5%	35 19.1%	96 16.8%	0 0.0%	149
	I am not sure	0 0.0%	1 .6%	1 .4%	11 2.0%	0 0.0%	13
	Total	16	124	183	575	1	899

<sup>14</sup> Note respondents could select all that applied

Table 40 - Access to a physiotherapist by time since diagnosis (Wales)<sup>15</sup>

Wales		Time since diagnosis					Total
		Less than 12 months ago	1-5 years ago	Between 5-10 years ago	More than 10 years ago	I don't know	
<b>In the past 12 months, have you seen a physiotherapist in relation to your MS?</b>	Yes, from the NHS	4 27.1%	53 43.0%	39 35.8%	120 40.4%	1 100.0%	216
	Yes, privately	0 0.0%	5 3.7%	3 3.2%	19 6.3%	0 0.0%	27
	Yes, from a charity or voluntary organisation	0 0.0%	7 5.3%	3 2.8%	16 5.4%	0 0.0%	26
	Yes, from somewhere else	1 9.9%	0 0.0%	0 0.0%	5 1.6%	0 0.0%	6
	No, and I have not needed to	6 41.4%	43 34.6%	37 34.6%	85 28.6%	0 0.0%	171
	No, but I needed to	3 21.7%	14 11.0%	23 21.7%	58 19.4%	0 0.0%	98
	I am not sure	0 0.0%	4 3.1%	3 3.1%	6 2.0%	0 0.0%	13
	<b>Total</b>	<b>14</b>	<b>124</b>	<b>108</b>	<b>297</b>	<b>1</b>	<b>543</b>

<sup>15</sup> Note respondents could select all that applied

## Support for mood and emotional issues

Table 41 - Access to support for mood or emotional issues<sup>16</sup>

		Nation				UK
		England	Northern Ireland	Scotland	Wales	
<b>Have you received sufficient support for mood or emotional issues?</b>	Yes, from the NHS	1456 16.5%	59 16.5%	140 15.3%	72 12.8%	1727 16.2%
	Yes, from a charity or voluntary organisation	252 2.9%	16 4.4%	39 4.3%	9 1.6%	316 3.0%
	Yes, from a private company or individual	181 2.1%	3 .8%	19 2.1%	10 1.8%	212 2.0%
	Yes, from somewhere else	290 3.3%	7 2.0%	30 3.3%	18 3.3%	346 3.2%
	No, and I have not needed support	4728 53.7%	169 47.2%	491 53.6%	288 51.6%	5677 53.4%
	No, but I needed support/more support	1792 20.4%	94 26.2%	195 21.3%	155 27.7%	2236 21.0%
	I am not sure	277 3.1%	16 4.4%	28 3.0%	14 2.6%	335 3.1%
	Total	8976 101.9%	364 101.5%	943 102.9%	566 101.4%	10848 102.0%
	Percentage of respondents who received support	22.8%	22.1%	22.1%	18.1%	22.5%

16 Percentages will sum to greater than 100% as multiple answers were possible

Table 42 - Access to support for mood or emotional issues by time since diagnosis (UK)<sup>17</sup>

UK	Time since diagnosis					Total
	Less than 12 months ago	1-5 years ago	Between 5-10 years ago	More than 10 years ago	I don't know	
Yes, from the NHS	44 22.2%	278 19.0%	361 18.3%	974 14.6%	0 0.0%	1656
Yes, from a charity or voluntary organisation	9 4.5%	69 4.7%	62 3.1%	167 2.5%	0 0.0%	306
Yes, from a private company or individual	7 3.7%	26 1.8%	40 2.1%	130 1.9%	0 0.0%	204
Yes, from somewhere else	6 3.2%	56 3.8%	74 3.7%	200 3.0%	2 13.8%	339
No, and I have not needed support	63 31.8%	685 46.8%	976 49.6%	3796 56.9%	10 55.7%	5530
No, but I needed support/more support	68 34.3%	363 24.8%	461 23.4%	1273 19.1%	5 30.4%	2169
I am not sure	12 5.8%	36 2.4%	43 2.2%	228 3.4%	0 0.0%	319
<b>Total</b>	<b>197</b>	<b>1465</b>	<b>1966</b>	<b>6672</b>	<b>18</b>	<b>10318</b>

<sup>17</sup> Note respondents could select all that applied

Table 43 - Access to support for mood or emotional issues by time since diagnosis (England)<sup>18</sup>

England		Time since diagnosis					Total
		Less than 12 months ago	1-5 years ago	Between 5-10 years ago	More than 10 years ago	I don't know	
<b>Have you received enough support for mood or emotional issues?</b>	Yes, from the NHS	40 25.5%	225 20.0%	297 18.6%	834 14.8%	0 0.0%	1396
	Yes, from a charity or voluntary organisation	8 4.9%	44 3.9%	52 3.2%	140 2.5%	0 0.0%	243
	Yes, from a private company or individual	7 4.8%	19 1.7%	38 2.4%	109 1.9%	0 0.0%	173
	Yes, from somewhere else	2 1.4%	52 4.6%	64 4.0%	164 2.9%	2 16.7%	283
	No, and I have not needed support	41 26.8%	535 47.4%	794 49.8%	3227 57.1%	8 53.2%	4605
	No, but I needed support/more support	54 35.0%	261 23.2%	360 22.6%	1062 18.8%	4 30.1%	1742
	I am not sure	12 7.5%	25 2.2%	35 2.2%	193 3.4%	0 0.0%	265
	<b>Total</b>	<b>155</b>	<b>1128</b>	<b>1595</b>	<b>5647</b>	<b>15</b>	<b>8539</b>

<sup>18</sup> Note respondents could select all that applied

Table 44 - Access to support for mood or emotional issues by time since diagnosis (Northern Ireland)<sup>19</sup>

Northern Ireland		Time since diagnosis					Total
		Less than 12 months ago	1-5 years ago	Between 5-10 years ago	More than 10 years ago	I don't know	
<b>Have you received enough support for mood or emotional issues?</b>	Yes, from the NHS	2 14.4%	17 18.7%	14 18.2%	21 13.6%	0 0.0%	54
	Yes, from a charity or voluntary organisation	1 9.3%	9 9.9%	2 3.1%	3 1.9%	0 0.0%	16
	Yes, from a private company or individual	0 0.0%	2 2.4%	0 0.0%	1 0.4%	0 0.0%	3
	Yes, from somewhere else	0 0.0%	3 3.9%	0 0.0%	4 2.4%	0 0.0%	7
	No, and I have not needed support	7 50.7%	30 33.3%	42 55.6%	83 52.4%	1 40.5%	163
	No, but I needed support/more support	4 25.5%	28 30.7%	12 16.2%	42 26.7%	1 59.5%	87
	I am not sure	0 0.0%	6 6.6%	5 7.0%	5 2.9%	0 0.0%	16
	<b>Total</b>	<b>15</b>	<b>90</b>	<b>76</b>	<b>158</b>	<b>2</b>	<b>340</b>

<sup>19</sup> Note respondents could select all that applied

Table 45 - Access to support for mood or emotional issues by time since diagnosis (Scotland)<sup>20</sup>

Scotland		Time since diagnosis					Total
		Less than 12 months ago	1-5 years ago	Between 5-10 years ago	More than 10 years ago	I don't know	
<b>Have you received enough support for mood or emotional issues?</b>	Yes, from the NHS	2 14.9%	17 13.5%	32 17.2%	85 14.9%	0 0.0%	136
	Yes, from a charity or voluntary organisation	0 0.0%	15 11.9%	5 2.7%	20 3.4%	0 0.0%	39
	Yes, from a private company or individual	0 0.0%	5 4.0%	1 0.4%	13 2.2%	0 0.0%	18
	Yes, from somewhere else	2 14.9%	1 0.8%	9 5.0%	17 3.0%	0 0.0%	30
	No, and I have not needed support	8 53.9%	55 44.6%	93 49.9%	321 56.4%	1 100.0%	478
	No, but I needed support/more support	4 31.3%	39 31.4%	49 26.2%	101 17.8%	0 0.0%	194
	I am not sure	0 0.0%	1 1.1%	2 1.2%	21 3.7%	0 0.0%	25
	<b>Total</b>	<b>14</b>	<b>123</b>	<b>187</b>	<b>569</b>	<b>1</b>	<b>894</b>

<sup>20</sup> Note respondents could select all that applied

Table 46 - Access to support for mood or emotional issues by time since diagnosis (Wales)

Wales		Time since diagnosis					Total
		Less than 12 months ago	1-5 years ago	Between 5-10 years ago	More than 10 years ago	I don't know	
Have you received enough support for mood or emotional issues?	Yes, from the NHS	0 0.0%	19 15.6%	18 16.6%	33 11.2%	0 0.0%	71
	Yes, from a charity or voluntary organisation	0 0.0%	1 1.1%	2 2.2%	4 1.5%	0 0.0%	8
	Yes, from a private company or individual	0 0.0%	0 0.0%	2 1.7%	8 2.7%	0 0.0%	10
	Yes, from somewhere else	2 15.3%	0 0.0%	1 0.7%	16 5.2%	0 0.0%	18
	No, and I have not needed support	6 46.1%	66 53.2%	46 42.8%	165 55.4%	1 100.0%	284
	No, but I needed support/more support	5 38.6%	35 28.5%	39 36.7%	67 22.5%	0 0.0%	147
	I am not sure	0 0.0%	3 2.8%	1 0.7%	10 3.2%	0 0.0%	14
	Total	14	124	108	298	1	544

## Care planning

Table 47 - Key contact for health care and support

		Nation				UK
		England	Northern Ireland	Scotland	Wales	
Who is the key contact for any health care or support in relation to your MS?	My GP	1579 20.4%	81 27.1%	223 27.3%	82 16.0%	1964 21.0%
	My MS nurse	3479 45.0%	126 42.3%	345 42.1%	304 59.4%	4254 45.5%
	My neurologist	582 7.5%	34 11.6%	52 6.4%	19 3.6%	687 7.3%
	My carer / a member of my family	1144 14.8%	33 11.1%	104 12.7%	66 12.9%	1347 14.4%
	No one	419 5.4%	3 1.2%	36 4.4%	12 2.4%	470 5.0%
	I am not sure	522 6.8%	20 6.8%	59 7.2%	29 5.7%	631 6.7%
	Total	7724 100.0%	298 100.0%	819 100.0%	512 100.0%	9353 100.0%
	Multiple responses given	1053	58	91	55	1257

Table 48 – Key contact for health care and support by information about available MS drugs (UK)

UK		Key contact						Total	
		GP	MS Nurse	Neurologist	Carer/ a member of my family	No one	I am not sure		Multiple responses given
<b>Have you received enough information from your health professionals about drugs available to support the treatment of your MS?</b>	Yes, I have been provided with enough information	439 22.8%	2142 51.1%	304 45.0%	291 22.3%	64 13.9%	131 21.2%	458 38.4%	3829 36.9%
	No, I have not been provided with enough information	639 33.2%	864 20.6%	156 23.1%	514 39.4%	149 32.3%	203 32.9%	354 29.6%	2879 27.8%
	No, I have not sought this information from health professionals	846 44.0%	1188 28.3%	215 31.9%	498 38.2%	249 53.9%	283 45.9%	382 32.0%	3661 35.3%
	Total	1924 100.0%	4194 100.0%	675 100.0%	1303 100.0%	462 100.0%	617 100.0%	1194 100.0%	10369 100.0%
	Total need	56.0%	71.7%	68.1%	61.8%	46.1%	54.1%	68.0%	64.7%
	Need met	40.7%	71.3%	66.1%	36.1%	30.0%	39.2%	56.4%	57.1%

Table 49 - Key contact for health care and support by information about available MS drugs (England)

England		Key contact						Total	
		My GP	My MS nurse	My neurologist	My carer / a member of my family	No one	I am not sure		Multiple responses given
<b>Have you received enough information from your health professionals about drugs available to support the treatment of your MS?</b>	Yes, I have been provided with enough information	336 21.7%	1751 51.1%	262 46.0%	247 22.3%	59 14.4%	105 20.5%	391 38.9%	3151 36.7%
	No, I have not been provided with enough information	514 33.2%	691 20.2%	130 22.8%	430 38.9%	132 32.1%	159 31.1%	290 28.9%	2346 27.4%
	No, I have not sought this information from health professionals	696 45.0%	986 28.8%	178 31.2%	429 38.8%	220 53.5%	247 48.3%	323 32.2%	3079 35.9%
	Total	1546 100.0%	3428 100.0%	570 100.0%	1106 100.0%	411 100.0%	511 100.0%	1004 100.0%	8576 100.0%
	Total need	55.0%	71.2%	68.8%	61.2%	46.5%	51.7%	67.8%	
	Need met	39.5%	71.7%	66.8%	36.5%	30.9%	39.8%	57.4%	

Table 50 - Key contact for health care and support by information about available MS drugs (Northern Ireland)

Northern Ireland		Key contact						Total	
		My GP	My MS nurse	My neurologist	My carer / a member of my family	No one	I am not sure		Multiple responses given
<b>Have you received enough information from your health professionals about drugs available to support the treatment of your MS?</b>	Yes, I have been provided with enough information	31 39.7%	63 50.0%	15 44.1%	11 33.3%	1 33.3%	5 26.3%	25 47.2%	151 43.6%
	No, I have not been provided with enough information	25 32.1%	28 22.2%	6 17.6%	14 42.4%	1 33.3%	7 36.8%	23 43.4%	104 30.1%
	No, I have not sought this information from health professionals	22 28.2%	35 27.8%	13 38.2%	8 24.2%	1 33.3%	7 36.8%	5 9.4%	91 26.3%
	Total	78 100.0%	126 100.0%	34 100.0%	33 100.0%	3 100.0%	19 100.0%	53 100.0%	346 100.0%
	Total need	71.8%	72.2%	61.8%	75.8%	66.7%	63.2%	90.6%	
	Need met	55.4%	69.2%	71.4%	44.0%	50.0%	41.7%	52.1%	

Table 51 - Key contact for health care and support by information about available MS drugs (Scotland)

Scotland		Key contact						Total	
		My GP	My MS nurse	My neurologist	My carer / a member of my family	No one	I am not sure		Multiple responses given
<b>Have you received enough information from your health professionals about drugs available to support the treatment of your MS?</b>	Yes, I have been provided with enough information	51 23.3%	188 55.5%	22 42.3%	26 25.7%	2 5.6%	18 31.6%	30 34.9%	337 37.9%
	No, I have not been provided with enough information	65 29.7%	61 18.0%	12 23.1%	34 33.7%	13 36.1%	24 42.1%	19 22.1%	228 25.6%
	No, I have not sought this information from health professionals	103 47.0%	90 26.5%	18 34.6%	41 40.6%	21 58.3%	15 26.3%	37 43.0%	325 36.5%
	Total	219 100.0%	339 100.0%	52 100.0%	101 100.0%	36 100.0%	57 100.0%	86 100.0%	890 100.0%
	Total need	53.0%	73.5%	65.4%	59.4%	41.7%	73.7%	57.0%	
	Need met	44.0%	75.5%	64.7%	43.3%	13.3%	42.9%	61.2%	

Table 52 - Key contact for health care and support by information about available MS drugs (Wales)

Wales		Key contact						Total	
		My GP	My MS nurse	My neurologist	My carer / a member of my family	No one	I am not sure		Multiple responses given
<b>Have you received enough information from your health professionals about drugs available to support the treatment of your MS?</b>	Yes, I have been provided with enough information	21 25.9%	141 46.5%	4 22.2%	8 12.3%	1 8.3%	3 10.0%	12 24.0%	190 34.0%
	No, I have not been provided with enough information	35 43.2%	84 27.7%	7 38.9%	36 55.4%	3 25.0%	13 43.3%	21 42.0%	199 35.6%
	No, I have not sought this information from health professionals	25 30.9%	78 25.7%	7 38.9%	21 32.3%	8 66.7%	14 46.7%	17 34.0%	170 30.4%
	Total	81 100.0%	303 100.0%	18 100.0%	65 100.0%	12 100.0%	30 100.0%	50 100.0%	559 100.0%
	Total need	69.1%	74.3%	61.1%	67.7%	33.3%	53.3%	66.0%	
	Need met	37.5%	62.7%	36.4%	18.2%	25.0%	18.8%	36.4%	

Table 53 - Extent professionals who plan care work well together

		Nation				UK
		England	Northern Ireland	Scotland	Wales	
<b>To what extent do you feel that the professionals who help plan your care work well together?</b>	Completely	1069 12.7%	55 16.5%	129 14.7%	80 14.7%	1333 13.1%
	To some extent	3037 36.1%	129 39.0%	306 34.7%	184 33.7%	3656 35.9%
	Not at all	1388 16.5%	49 14.8%	111 12.6%	96 17.6%	1643 16.2%
	I am not sure	1173 13.9%	47 14.3%	132 14.9%	71 13.1%	1423 14.0%
	Not applicable	1747 20.8%	51 15.4%	204 23.1%	113 20.8%	2116 20.8%
	Total	8413 100.0%	331 100.0%	882 100.0%	544 100.0%	10171 100.0%

Table 54 - Care plan and care plan review

		Nation				UK
		England	Northern Ireland	Scotland	Wales	
<b>In the past 12 months, have you been offered a care plan and/or care plan review for your health care? <sup>21</sup></b>	Yes, I have been offered a care plan	603 6.9%	40 11.4%	54 5.9%	25 4.5%	722 6.8%
	Yes, I have been offered a care plan review	449 5.1%	20 5.7%	54 5.9%	25 4.5%	548 5.2%
	No	7198 82.5%	276 78.4%	763 83.6%	474 85.6%	8711 82.6%
	I am not sure	479 5.5%	16 4.5%	42 4.6%	30 5.4%	567 5.4%
	Total	8729 100.0%	352 100.0%	913 100.0%	554 100.0%	10548 100.0%

21 In the questionnaire a care plan was described as 'a plan made with your health professional that sets out what your care and support needs are and how they will be met. A review is where your needs are re-assessed and changes can be made to the plan'.

## 4. Appendices

### Appendix 1 - MY MS My Needs questionnaire 2016

#### Background information

**1. Are you male or female?**

- Female
- Male
- Prefer not to say

**2. How old are you?**

- 18-29
- 30-39
- 40-49
- 50-59
- 60-69
- 70 to 79
- 80 or over
- Prefer not to say

**3. What type of MS do you have?**

- Relapsing remitting MS
- Secondary progressive MS with relapses
- Secondary progressive MS without relapses
- Primary progressive MS
- I don't know

**4. How long ago were you diagnosed as having MS by your neurologist?**

- Less than 12 months ago
- 1-5 years ago
- Between 5-10 years ago
- More than 10 years ago
- I don't know

#### Your care needs

Care and support (social care) can enable you to remain independent and carry out the practical tasks of everyday living, like washing and dressing, or getting out and about. This might be provided by family, friends, social services, or a combination of these.

**5. In the past 12 months, have you received social care support?** i.e. support from someone for the kind of practical tasks described above

- Yes, I have received all the support I needed
- Yes, I have received some support but not enough
- No, and I have not needed to
- No, but I needed to
- I am not sure

[ROUTING: If 'No and I have not needed to', go to Q11]

**6. What sort of practical tasks do you NEED support with?** (Tick all that apply)

- Getting up in the morning
- Going to bed
- Washing/bathing/personal care
- Meals/eating
- Cooking

- Getting out of the house
- Shopping
- Cleaning/laundry
- Other
- Not sure

**6b. What sort of practical tasks do you RECEIVE support with?** (Tick all that apply)

- Getting up in the morning
- Going to bed
- Washing/bathing/personal care
- Meals/eating
- Cooking
- Getting out of the house
- Shopping
- Cleaning/laundry
- Other
- Not sure

**7. In the past 12 months, have you received care and support in relation to your MS for practical tasks from any of the following?**  
(Tick all that apply)

- Your local council (or Trust in NI) or social services
- A charity or voluntary sector organisation
- Friends or family (unpaid)
- An occupational therapy service
- A private home care company
- A private individual e.g. cleaner or cook
- A care home or nursing home
- Other
- I am not sure

**8. Who pays for your social care?** For example this could be paid for by the government i.e. your local council or social services, or the NHS.

- The government does
- I do/my family does
- Partly the government and partly me/my family
- I am not sure

**9. In the past 12 months, have you had a social care assessment and/or review from your local council (or Trust in NI) for your care and support needs?**

- Yes
- No, but I needed one
- No, but I did not need one
- I am not sure
- I only receive unpaid care and support from family or friends

**10. In the past 12 months, have you been offered a care plan and/or care plan review for your social care?** A care plan is a plan made with social services that sets out what your care and support needs are and how they will be met. A review is where your needs are re-assessed and changes can be made to the plan.

- Yes, I have been offered a care plan
- Yes, I have been offered a care plan review
- No
- I am not sure

## Employment

**11. Are you currently in paid employment?**

- Yes, employed / self employed full time
- Yes, employed / self employed part time
- No, looking for work
- No, not looking for work
- No, retired
- No, student

[ROUTING: If 'No retired' or 'No student' or 'No not looking for work, go to Q16]

**12. In the past 12 months, have you received support to help you find employment?**

For example government programmes such as Work Choice, support from Job Centre advisors etc.

- Yes
- No, and I have not needed support
- No, but I needed support
- I am not sure

[ROUTING: If No go to Q14]

**13. If yes, where have you received support from?** (Tick all that apply)

- Job Centre
- Charity/ Voluntary organisation
- Your local council (or Trust in NI)
- Friends or family
- Other

**14. In the past 12 months, have you received support to remain in employment?** For example the Access to Work Scheme, adapted working arrangements or workplace adaptations

- Yes
- No, and I have not needed support
- No, but I needed support
- I am not sure

[ROUTING: If no go to Q16]

**15. If yes, where have you received support from?** (Tick all that apply)

- Government e.g. 'Access to work'
- My local council (or Trust in NI)
- NHS or health service
- A welfare or money advice service
- My employer
- Charity/ Voluntary sector
- Other
- Not applicable

**16. Have you done any of the following as a result of your MS?** (Tick all that apply)

- Changed working hours
- Changed jobs or roles
- Retired early
- Left work entirely
- Changed location
- Made physical changes / adaptations to my work environment
- Other
- I haven't had to change anything in relation to my work

## Income and benefits

**17. Which would you say comes closest to your feelings about your current household income?**

- Living really comfortably on current income
- Living comfortably on current income
- Neither comfortable nor struggling on current income
- Struggling on current income
- Really struggling on current income

**18. Do you currently receive any of the following disability benefits?** (Tick all that apply)

- Employment Support Allowance (ESA)
- Incapacity Benefit (IB)
- Disability Living Allowance (DLA)
- Personal Independence Payment (PIP)
- None of the above
- I am not sure

**19. In the last 12 months, have you used the Motability Scheme?** The Motability Scheme provides access to adapted vehicles, wheelchairs, and scooters and is available to those receiving the higher rate mobility component of DLA or PIP

- Yes
- Yes, but I have now lost my entitlement and am no longer able to access the Scheme
- No, I have needed support from the Scheme but have been unable to access it
- No, and I have not needed to access the Scheme
- I am not sure

## Powered wheelchairs

**20. Do you use a powered wheelchair to help with your mobility?**

- Yes
- No, and I do not need one
- No, but I would benefit from one

**21. If you use a powered wheelchair, did you/your family pay for it?**

- Yes, I/we paid the entire cost
- Yes, I/we paid part of the cost
- No

[ROUTING: If no go to Q22]

## Healthcare and community services

**22. In the past 12 months, have you seen an MS specialist nurse in relation to your MS?**

- Yes
- No, and I have not needed to
- No, but I needed to
- I am not sure

[ROUTING: If no go to Q24]

**23. If yes, was this** (Tick all that apply)

- In a specialist clinic in a hospital setting
- In an outreach clinic in a community setting
- In your home
- By telephone
- By email

**24. In the past 12 months, have you seen a neurologist in relation to your MS?**

- Yes
- No, and I have not needed to
- No, but I needed to
- I am not sure

**25. In the past 12 months, have you seen a specialist about continence advice in relation to your MS?** (e.g. bladder or bowel advice)

- Yes
- No, and I have not needed to
- No, but I needed to
- I am not sure

**26. In the past 12 months, have you received sufficient support for mood or emotional issues?** i.e. from health or community services rather than friends or family

- Yes from the NHS
- Yes from a charity or voluntary organisation
- Yes from a private company or individual
- Yes from somewhere else
- No, and I have not needed support
- No, but I needed support/more support
- I am not sure

**27. In the past 12 months, have you seen a physiotherapist in relation to your MS?**

- Yes, from the NHS
- Yes, privately
- Yes, from a charity or voluntary organisation
- Yes from somewhere else
- No, and I have not needed to
- No, but I needed to
- I am not sure

[ROUTING: If 'no and I have not needed to' go to Q29]

**28. If you have needed to be seen by a physiotherapist in the past 12 months, have you been able to contact them directly (i.e. self referral)?**

- Yes
- No, I need to be referred by another healthcare professional
- Not sure

**29. In the past 12 months, have you received support so that you can keep physically active?** For example, help to attend exercise classes, or use sports and leisure facilities

- Yes from the NHS
- Yes from my local council (or Trust in NI)
- Yes from a charity or voluntary organisation
- Yes from somewhere else
- No, and I have not needed to
- No, but I needed to
- I am not sure

## Care coordination

### 30. Who is the key contact for any healthcare or support in relation to your MS?

- My GP
- My MS nurse
- My neurologist
- My carer / a member of my family
- No one
- I am not sure

### 31. In the past 12 months, have you been offered a care plan and/or care plan review for your healthcare? A care plan is a plan made with your health professional that sets out what your care and support needs are and how they will be met. A review is where your needs are re-assessed and changes can be made to the plan.

- Yes, I have been offered a care plan
- Yes, I have been offered a care plan review
- No
- I am not sure

### 32. To what extent do you feel that the professionals who help plan your care work well together? E.g. from your GP, hospital, social care

- Completely
- To some extent
- Not at all
- I am not sure
- Not applicable

## Access to therapies

This section asks about some therapies that are specifically licenced for MS and are possible treatment options for some people with MS. These will not be suitable for everyone with MS and there may be other therapies or drugs not listed.

### 33. Below is a list of disease modifying therapies that are licensed specifically for MS at present. Please select from the list all of the drugs you are currently taking:

- Aubagio (Teriflunomide)
- Avonex (beta interferon 1a)
- Betaferon (beta interferon 1b)
- Copaxone (glatiramer acetate)
- Extavia (beta interferon 1b)
- Gilenya (fingolimod)
- Lemtrada (Alemtuzumab)
- Plegridy (peginterferon beta 1a)
- Rebif (beta interferon 1a)
- Tecfidera (Dimethyl fumarate)
- Tysabri (natalizumab)
- I am not currently taking any of the drugs listed

### 34. Below is a list of symptom management therapies that are licensed specifically for MS at present. Please select from the list all of the drugs you are currently taking:

- Sativex (delta-9-tetrahydrocannabinol, cannabidiol)
- Fampyra (Fampridine)
- Botox (onabotulinumtoxin A)
- I am not currently taking any of the drugs listed

### 35. In the last 12 months, have you requested sativex?

- Yes, and my request was accepted
- Yes, and my request was turned down
- No
- I am not sure

**36. In the last 12 months, have you requested functional electrical stimulation (FES)?** FES is a treatment that uses the application of small electrical charges to improve mobility

- Yes, and my request was accepted
- Yes, and my request was turned down
- No
- I am not sure

**37. Have you received enough information from your health professionals about drugs available to support the treatment of your MS?**

- Yes, I have been provided with enough information
- No, I have not been provided with enough information
- No, I have not sought this information from health professionals

## Information and advocacy

**38. In the past 12 months, have you received sufficient information in relation to your MS?**

- Yes, I've received sufficient information
- No, I have not needed any information
- No, I needed more information

**39. In the past 12 months, have you used an advocacy service?** Advocacy services help people to put forward their views or speak or act on their behalf, for example to help them access the services they need

- Yes
- No, and I have not needed to
- No, but I needed to
- I am not sure

## Before you go

**40. Could we contact you in the future to take part in further research we think may be relevant to you, based on your responses to this survey?**

Your personal information will be handled securely and your responses would be anonymised before analysis.

- Yes, and I understand this does not mean I would have to take part in any future research
- No, I would prefer you not to contact me in this way

Thank you for taking the time to complete this survey. Your responses will be invaluable in helping the MS Society improve the care and support available to all people affected by MS.

## Appendix 2- Questionnaire cover letter



[Address line 1]  
[Address line 2]  
[Address line 3]  
[Address line 4]  
[Address line 5]

Dear [name]

### **My MS My Needs – take part in our survey**

We would like to invite you to take part in an important survey to understand whether people with MS are getting the treatments, services and support they need. In 2012 over 10,000 people with MS responded to My MS My Needs, making it a powerful voice for change. The findings helped us ensure our new Strategy was based on what was important to people with MS, and led us to successfully campaign for changes in national guidelines on the care and treatment of MS.

Four years on, we want to know whether anything has changed and what we should be doing next. Your responses will help us campaign for improved services across the whole of the UK, and enable us to focus our work with local services in areas where improvements are needed. **Every response counts.** We want to make sure we are representing the views of everyone with MS and have the numbers to really persuade decision makers to take action.

Please return the questionnaire in the FREEPOST envelope enclosed (no stamp required).

Participation in the survey is voluntary and should only take about 15 minutes. If you decide you don't want to take part and don't want to receive any reminders, either return the blank questionnaire or call the Research Team number below to opt out.

If you need help to complete the questionnaire, please feel free to ask someone. But the answers should be given from the point of view of the person with MS, rather than the person who is helping. For each question please cross  clearly inside one box using a black or blue pen. Don't worry if you make a mistake; simply fill in the box  and put a cross  in the correct box.

Your responses will be confidential and we will not analyse or report our findings in a way that would allow you to be identified.

If you have any questions about the survey, or you need some help filling in it, please contact the Research Team at [research@mssociety.org.uk](mailto:research@mssociety.org.uk) or on 020 8438 0822. Alternatively, if you'd like to talk to someone about any of the issues it raises you can contact the MS Helpline free of charge on 0808 800 8000 (Monday to Friday 9am-9pm) or by email to [helpline@mssociety.org.uk](mailto:helpline@mssociety.org.uk).

**Thank you**

Nick Rijke

Executive Director of Policy & Research, MS Society



Please return this questionnaire to:  
MS Society, FREEPOST RRXA-EGBL-EHKC, Wembley, HA0 4PE

9920235493

## **We're the MS Society.**

Our community is here for you through the highs, lows and everything in between.  
We understand what life's like with MS.

Together, we are strong enough to stop MS.



### **Contact us**

MS National Centre 020 8438 0700  
info@mssociety.org.uk

MS Helpline Freephone 0808 800 8000 (weekdays 9am-9pm)  
helpline@mssociety.org.uk

### **Online**

mssociety.org.uk  
www.facebook.com/MSSociety  
twitter.com/mssocietyuk

### **MS Society Scotland**

0131 335 4050  
msscotland@mssociety.org.uk

### **MS Society Northern Ireland**

028 9080 2802  
nireception@mssociety.org.uk

### **MS Society Cymru**

mscymru@mssociety.org.uk

Multiple Sclerosis Society.  
Registered charity nos. 1139257 / SC041990.  
Registered as a limited company by guarantee  
in England and Wales 07451571.

 **Let's stop MS together**

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