

Appendix 1 – data tables for UK and nations

See My MS My Needs 2016: access to treatment and health care technical report for additional methodological details.

The initial survey was run in 2013. Together, the results of the My MS My Needs surveys provide an opportunity to understand in detail how people with MS feel about their treatment, care and support. While the 2016 questionnaire was broadly similar to the 2013 iteration, some questions were changed, removed or added, meaning that comparisons cannot always be made. Where possible the original 2013 data has been used to ensure consistency with 2016 analysis methods. Furthermore, the samples were different for the two surveys, so while trends can be identified direct comparisons are not always possible.

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.

'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.

'Need met' is calculated as the proportion of respondents who responded 'Yes', out of those who responded 'Yes' or 'No, but I needed to'.

The data tables presented here are from the UK, followed by England, Scotland, Wales and Northern Ireland. There were not enough responses to some questions to give the figures at individual nation level, where this is the case these tables have been left out. Where there were less than five respondents in a category, numbers have been excluded from the data tables provided.

Respondents

10,888 people with MS from across the UK 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.

Survey administration

Table 1.1 - Collection method by nation

	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%

1. Demographic breakdown by nation

Table 1.2 - Gender

	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%

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Table 1.3 - Age

	Nation				UK	
	England	Northern Ireland	Scotland	Wales		
How old are you?	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 1.4 - Type of MS

	Nation				UK	
	England	Northern Ireland	Scotland	Wales		
What type of MS do you have?	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%

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Table 1.5 - Time since diagnosis

	Nation				UK	
	England	Northern Ireland	Scotland	Wales		
How long ago were you diagnosed as having multiple sclerosis by your neurologist?	Less than 12 months ago	156 1.8%	15 4.2%	16 1.7%	14 2.5%	200 1.9%
	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%

2. UK tables

Table 2.1a – Need and access to social care support in 2016

	Frequency	Percent	
In the past 12 months, have you received social care support?	Yes, I have received all the support I needed	4142	38.0%
	Yes, I have received some support but not enough	1525	14.0%
	No, and I have not needed to	4177	38.4%
	No, but I needed to	595	5.5%
	I am not sure	176	1.6%
	No answer	273	2.5%
	Total	10888	100.0%
	Total need	6261	57.5%
	Need met	4142	66.2%

Table 2.1b – Need and access to social care support in 2013

	Frequency	Percent	
In the past 12 months have you received social care support?	Yes	2752	26.1%
	No, but I needed to	949	9.0%
	No, and I have not needed to	6163	58.5%
	I am not sure	426	4.0%
	No answer	240	2.3%
	Total	10530	100.0%
	Total need	3701	35.1%
	Need met	2752	74.4%

Table 2.2 – Paying for social care in 2016 and 2013

	2016		2013	
	Frequency	Percent	Frequency	Percent
Who pays for your social care?				
The government does	1038	18.3%	1248	45.3%
I do/my family does	2188	38.6%	415	15.1%
Partly the government and partly me/my family	1128	19.9%	845	30.7%
I am not sure	508	9.0%	126	4.6%
No answer	805	14.2%	118	4.3%
Total	5667	100.0%	2752	100.0%

Table 2.3 – Practical support needs¹

	Frequency	Percent
What sort of practical tasks do you NEED support with?		
Getting up in the morning	2504	40.0%
Going to bed	2208	35.3%
Washing/bathing/personal care	3337	53.3%
Meals/eating	2663	42.5%
Cooking	4517	72.1%
Getting out of the house	4252	67.9%
Shopping	4954	79.1%
Cleaning/laundry	4965	79.3%
Other	1352	21.6%
Not sure	162	2.6%

¹ Percentage calculated out of respondents identifying a need in question 5

Table 2.4 - Practical support receiving²

What sort of practical tasks do you RECEIVE support with?	Frequency	Percent
	Getting up in the morning	2344
Going to bed	2141	34.2%
Washing/bathing/personal care	3047	48.7%
Meals/eating	2588	41.3%
Cooking	4079	65.2%
Getting out of the house	3880	62.0%
Shopping	4450	71.1%
Cleaning/laundry	4443	71.0%
Other	1161	18.5%
Not sure	158	2.5%

Table 2.5 – Social care plan or review offered by need met for social care support

	In the past 12 months, have you been offered a care plan and/or care plan review for your social care?						
	Yes, I have been offered a care plan	Yes, I have been offered a care plan review	No	I am not sure	No answer	Total	
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	534 74.7%	289 70.3%	2564 60.0%	171 58.8%	585 57.4%	4143 61.7%
	Yes, I have received some support but not enough	159 22.2%	108 26.3%	1015 23.7%	86 29.6%	157 15.4%	1525 22.7%
	No, but I needed to	8 1.1%	6 1.5%	460 10.8%	7 2.4%	114 11.2%	595 8.9%
	I am not sure	7 1.0%	- -	128 3.0%	18 6.2%	20 2.0%	175 2.6%
	No answer	7 1.0%	6 1.5%	107 2.5%	9 3.1%	144 14.1%	273 4.1%
	Total	715 100.0%	411 100.0%	4274 100.0%	291 100.0%	1020 100.0%	6711 100.0%
	Need met	76.2%	71.7%	63.5%	64.8%	68.3%	

² Percentage calculated out of respondents identifying a need in question 5

Table 2.6 – Access to social care support by age

	How old are you?								
	18-29	30-39	40-49	50-59	60-69	70-79	80 or over	Total	
In the past 12 months, have you received social care support?	Yes, I have received all the support I needed	39 13.9%	332 26.5%	766 32.0%	1196 39.3%	1181 45.7%	486 46.5%	142 49.8%	4142 38.0%
	Yes, I have received some support but not enough	46 16.4%	149 11.9%	344 14.4%	498 16.4%	332 12.9%	113 10.8%	43 15.1%	1525 14.0%
	No, and I have not needed to	152 54.3%	683 54.5%	1049 43.8%	1076 35.3%	824 31.9%	326 31.2%	66 23.2%	4176 38.4%
	No, but I needed to	25 8.9%	63 5.0%	147 6.1%	170 5.6%	126 4.9%	53 5.1%	11 3.9%	595 5.5%
	I am not sure	11 3.9%	19 1.5%	40 1.7%	51 1.7%	33 1.3%	22 2.1%	- -	177 1.6%
	No answer	7 2.5%	8 .6%	49 2.0%	54 1.8%	86 3.3%	45 4.3%	22 7.7%	271 2.5%
	Total	280 100.0%	1254 100.0%	2395 100.0%	3045 100.0%	2582 100.0%	1045 100.0%	285 100.0%	10886 100.0%
	Total Need	39.3%	43.4%	52.5%	61.2%	63.5%	62.4%	68.8%	
	Need met	35.5%	61.0%	60.9%	64.2%	72.1%	74.5%	72.4%	

Table 2.7 – Need met for social care support by who pays

	Who pays for your social care? For example this could be paid for by the government e.g. 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	No answer	Total	
In the past 12 months, have you received social care support?	Yes, I have received all the support I needed	812 73.7%	1556 61.7%	816 67.1%	333 50.8%	626 51.7%	4143 61.7%
	Yes, I have received some support but not enough	226 20.5%	632 25.0%	313 25.7%	175 26.7%	178 14.7%	1524 22.7%
	No, but I needed to	29 2.6%	244 9.7%	46 3.8%	77 11.7%	198 16.3%	594 8.9%
	I am not sure	12 1.1%	49 1.9%	22 1.8%	48 7.3%	45 3.7%	176 2.6%
	No answer	23 2.1%	42 1.7%	20 1.6%	23 3.5%	165 13.6%	273 4.1%
	Total	1102 100.0%	2523 100.0%	1217 100.0%	656 100.0%	1212 100.0%	6710 100.0%
	Need met	76.1%	64.0%	69.4%	56.9%	62.5%	

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Table 2.8 – Access to social care by feelings about household income

	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	No answer	Total	
In the past 12 months, have you received social care support?	Yes, I have received all the support I needed	280 33.3%	1477 39.3%	1713 39.6%	441 34.1%	83 27.3%	147 40.1%	4141 38.1%
	Yes, I have received some support but not enough	31 3.7%	311 8.3%	726 16.8%	317 24.5%	88 28.9%	51 13.9%	1524 14.0%
	No, and I have not needed to	481 57.3%	1754 46.7%	1453 33.6%	341 26.4%	69 22.7%	79 21.5%	4177 38.4%
	No, but I needed to	25 3.0%	107 2.8%	263 6.1%	135 10.4%	41 13.5%	22 6.0%	593 5.4%
	I am not sure	10 1.2%	26 .7%	78 1.8%	37 2.9%	14 4.6%	10 2.7%	175 1.6%
	No answer	13 1.5%	81 2.2%	89 2.1%	23 1.8%	9 3.0%	58 15.8%	273 2.5%
	Total	840 100.0%	3756 100.0%	4322 100.0%	1294 100.0%	304 100.0%	367 100.0%	10883 100.0%
	Total need	40.0%	50.5%	62.5%	69.0%	69.7%	59.9%	
	Need met	83.3%	77.9%	63.4%	49.4%	39.2%	66.8%	

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Table 2.9 – Where received care and support from

	Frequency	Percent
Your local council (or Trust in Northern Ireland) or social services	1423	23.0%
A charity or voluntary sector organisation	525	8.5%
Friends or family (unpaid)	5298	85.5%
An occupational therapy service	1376	22.2%
A private home care company	688	11.1%
A private individual e.g. cleaner or cook	1554	25.1%
A care home or nursing home	205	3.3%
Other	371	6.0%
I am not sure	99	1.6%
<p>In the past 12 months, have you received care and support in relation to your MS for practical tasks from any of the following?</p>		
<p>People only receiving care from family and friends - n = 2411 (38.5% of those with a need)</p>		

Table 2.10 – Access to social care for respondents who need support with Activities of Daily Living (ADLs - essential support)

	Frequency	Percent
Yes, I have received all the support I needed	2729	64.8%
Yes, I have received some support but not enough	1024	24.3%
No, but I needed to	296	7.0%
I am not sure	75	1.8%
No answer	86	2.1%
Total	4211	100.0%
Need met	2729	67.4%
<p>In the past 12 months, have you received social care support?</p>		

Table 2.11 – Age of respondents who need support with ADLs (essential support)

	Frequency	Percent
18-29	67	1.6%
30-39	301	7.1%
40-49	779	18.5%
50-59	1236	29.4%
60-69	1200	28.5%
70-79	485	11.5%
80 or over	142	3.4%
Total	4211	100.0%
<p>How old are you?</p>		

Table 2.12 – Type of MS of respondents who need support with ADLs (essential support)

	Frequency	Percent
What type of MS do you have?		
Relapsing remitting MS	1006	23.9%
Secondary progressive MS with relapses	736	17.5%
Secondary progressive MS without relapses	1182	28.1%
Primary progressive MS	887	21.1%
I don't know	294	7.0%
No answer	106	2.5%
Total	4211	100.0%

Table 2.13 – Time since diagnosis of respondents who need support with ADLs (essential support)

	Frequency	Percent
How long ago were you diagnosed as having Multiple Sclerosis by your neurologist?		
Less than 12 months ago	41	1.0%
1-5 years ago	337	8.0%
Between 5-10 years ago	615	14.6%
More than 10 years ago	3058	72.6%
I don't know	12	0.3%
No answer	148	3.5%
Total	4211	100.0%

Table 2.14 – Who pays for social care for respondents who need support with ADLs (essential support)

	Frequency	Percent
Who pays for your social care? For example this could be paid for by the government e.g. your local council or social services, or the NHS.		
The government does	876	20.8%
I do/my family does	1478	35.1%
Partly the government and partly me/my family	917	21.8%
I am not sure	398	9.4%
No answer	542	12.9%
Total	4211	100%

Table 2.15 – Feelings about income for respondents who need support with ADLs (essential support)

		Frequency	Percent
Which would you say comes closest to your feelings about your current household income?	Living really comfortably on current income	197	4.7%
	Living comfortably on current income	1208	28.7%
	Neither comfortable nor struggling on current income	1841	43.7%
	Struggling on current income	635	15.1%
	Really struggling on current income	152	3.6%
	No answer	178	4.2%
	Total	4211	100.0%

Table 2.16 – Social care plan or review offered for respondents who need support with ADLs (essential support)

		Frequency	Percent
In the past 12 months, have you been offered a care plan and/or care plan review for your social care?	Yes, I have been offered a care plan	637	15.1%
	Yes, I have been offered a care plan review	373	8.9%
	No	2462	58.5%
	I am not sure	209	5.0%
	No answer	529	12.6%
	Total	4211	100.0%

Table 2.17 – Access to social care for respondents who only need support with Instrumental Activities of Daily Living (IADLs)

		Frequency	Percent
In the past 12 months, have you received social care support?	Yes, I have received all the support I needed	1175	59.8%
	Yes, I have received some support but not enough	456	23.2%
	No, but I needed to	220	11.2%
	I am not sure	66	3.3%
	No answer	47	2.4%
	Total	1963	100.0%
	Need met	1175	63.5%

Table 2.18 - Age of respondents who only need support with IADLs

	Frequency	Percent
How old are you?		
18-29	32	1.6%
30-39	218	11.1%
40-49	453	23.1%
50-59	606	30.9%
60-69	429	21.8%
70-79	176	8.9%
80 or over	50	2.6%
Total	1963	100.0%

Table 2.19 - Type of MS of respondents who only needed support with IADLs

	Frequency	Percent
What type of MS do you have?		
Relapsing remitting MS	820	41.8%
Secondary progressive MS with relapses	274	14.0%
Secondary progressive MS without relapses	391	19.9%
Primary progressive MS	294	15.0%
I don't know	146	7.5%
No answer	37	1.9%
Total	1963	100.0%

Table 2.20 - Time since diagnosis of respondents who only need support with IADLs

	Frequency	Percent
How long ago were you diagnosed as having Multiple Sclerosis by your neurologist?		
Less than 12 months ago	29	1.5%
1-5 years ago	260	13.3%
Between 5-10 years ago	387	19.7%
More than 10 years ago	1233	62.8%
I don't know	-	-
No answer	51	2.6%
Total	1963	100.0%

Table 2.21 – Who pays for social care for respondents who only need support with IADLs

	Frequency	Percent
Who pays for your social care?		
The government does	185	9.4%
I do/my family does	966	49.2%
Partly the government and partly me/my family	278	14.2%
I am not sure	213	10.8%
No answer	322	16.4%
Total	1963	100.0%

Table 2.22 – Feelings about income for respondents who only need support with IADLs

	Frequency	Percent
Which would you say comes closest to your feelings about your current household income?		
Living really comfortably on current income	115	5.8%
Living comfortably on current income	640	32.6%
Neither comfortable nor struggling on current income	822	41.9%
Struggling on current income	256	13.0%
Really struggling on current income	74	3.8%
No answer	57	2.9%
Total	1963	100.0%

Table 2.23 – Social care plan or review offered for respondents who only need support with IADLs

	Frequency	Percent
In the past 12 months, have you been offered a care plan and/or care plan review for your social care?		
Yes, I have been offered a care plan	70	3.6%
Yes, I have been offered a care plan review	33	1.7%
No	1595	81.3%
I am not sure	71	3.6%
No answer	195	9.9%
Total	1963	100.0%

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Table 2.24 - Practical tasks need support with by age

	What sort of practical tasks do you NEED support with?										Total
	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	
18-29	35 29.4%	- -	35 29.4%	32 26.3%	78 64.8%	60 50.0%	75 62.1%	74 62.0%	14 11.6%	25 21%	120
30-39	106 20.1%	79 14.9%	219 41.4%	175 33.2%	389 73.6%	303 57.3%	404 76.4%	406 76.7%	152 28.8%	15 3%	529
40-49	424 33.6%	331 26.2%	591 46.8%	499 39.6%	902 71.5%	763 60.5%	986 78.2%	974 77.2%	304 24.1%	46 4%	1261
50-59	714 38.3%	621 33.3%	960 51.5%	814 43.6%	1353 72.5%	1275 68.3%	1483 79.5%	1486 79.6%	418 22.4%	33 2%	1866
60-69	785 47.7%	742 45.1%	999 60.7%	781 47.5%	1239 75.3%	1208 73.5%	1337 81.3%	1334 81.1%	329 20.0%	28 2%	1644
70-79	335 50.2%	330 49.4%	409 61.2%	290 43.4%	452 67.7%	491 73.6%	522 78.1%	541 81.0%	112 16.8%	12 2%	668
80 or over	104 53.4%	102 52.2%	124 63.8%	71 36.7%	104 53.5%	151 77.7%	148 76.1%	151 77.6%	22 11.5%	- -	195
Total	2504	2208	3337	2663	4517	4252	4954	4965	1352	162	6282

Table 2.25 – Need met for social care for respondents only receiving support from family and friends

		Frequency	Percent
In the past 12 months, have you received social care support	Yes, I have received all the support I needed	1508	62.6%
	Yes, I have received some support but not enough	522	21.7%
	No, but I needed to	261	10.8%
	I am not sure	51	2.1%
	No answer	68	2.8%
	Total	2411	100%
	Need met	1508	65.8%

Table 2.26 – Who pays for social care by whether a social care plan or review offered

	In the past 12 months, have you been offered a care plan and/or care plan review for your social care?					
	Yes, I have been offered a care plan	Yes, I have been offered a care plan review	No	I am not sure	No answer	Total
The government does	314 43.9%	151 36.7%	410 9.6%	66 22.8%	161 15.8%	1102 16.4%
I do/my family does	104 14.5%	58 14.1%	2081 48.7%	64 22.1%	216 21.2%	2523 37.6%
Partly the government and partly me/my family	217 30.3%	164 39.9%	601 14.1%	74 25.5%	160 15.7%	1216 18.1%
I am not sure	29 4.1%	10 2.4%	497 11.6%	63 21.7%	58 5.7%	657 9.8%
No answer	51 7.1%	28 6.8%	685 16.0%	23 7.9%	425 41.7%	1212 18.1%
Total	715 100.0%	411 100.0%	4274 100.0%	290 100.0%	1020 100.0%	6710 100.0%

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Table 2.27 – Need met for social care support by type of MS

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	No answer	Total	
In the past 12 months, have you received social care support?	Yes, I have received all the support I needed	1173 56.7%	641 60.1%	1107 67.2%	834 66.6%	302 61.6%	85 45.9%	4142 61.7%
	Yes, I have received some support but not enough	494 23.9%	285 26.7%	343 20.8%	264 21.1%	92 18.8%	48 25.9%	1526 22.7%
	No, but I needed to	242 11.7%	83 7.8%	115 7.0%	93 7.4%	46 9.4%	16 8.6%	595 8.9%
	I am not sure	79 3.8%	22 2.1%	24 1.5%	24 1.9%	19 3.9%	7 3.8%	175 2.6%
	No answer	82 4.0%	35 3.3%	58 3.5%	38 3.0%	31 6.3%	29 15.7%	273 4.1%
	Total	2070 100.0%	1066 100.0%	1647 100.0%	1253 100.0%	490 100.0%	185 100.0%	6711 100.0%
	Need met	61.4%	63.5%	70.7%	70.0%	68.6%	57.0%	

Appendices:

Social care and the MS community in England: care and support analysis of the 2016 My MS My Needs survey

Table 2.28 – Offered a care plan or care plan review (excluding respondents who ticked 'No, and I have not needed to' for question 5)

		Frequency	Percent
In the past 12 months, have you been offered a care plan and/or care plan review for your social care?	Yes, I have been offered a care plan	715	10.7%
	Yes, I have been offered a care plan review	411	6.1%
	No	4274	63.7%
	I am not sure	292	4.3%
	No answer	1019	15.2%
	Total	6711	100.0%

Table 2.29 – Feelings about household income (excluding respondents who ticked 'No, and I have not needed to' for question 5)

		Frequency	Percent
Which would you say comes closest to your feelings about your current household income?	Living really comfortably on current income	361	5.4%
	Living comfortably on current income	2002	29.8%
	Neither comfortable nor struggling on current income	2870	42.8%
	Struggling on current income	953	14.2%
	Really struggling on current income	236	3.5%
	No answer	289	4.3%
	Total	6711	100.0%

3. England Tables

Table 3.1a – Need and access to social care support in 2016

		Frequency	Percent
In the past 12 months, have you received social care support?	Yes, I have received all the support I needed	3428	38.1%
	Yes, I have received some support but not enough	1234	13.7%
	No, and I have not needed to	3479	38.6%
	No, but I needed to	491	5.5%
	I am not sure	143	1.6%
	No answer	233	2.6%
	Total	9008	100.0%
	Total need	5153	57.2%
	Need met	3428	66.5%

Table 3.1b – Need and access to social care support in 2013

		Frequency	Percent
In the past 12 months have you received social care support?	Yes	2301	25.7%
	No, but I needed to	809	9.0%
	No, and I have not needed to	5298	59.1%
	I am not sure	355	4.0%
	No answer	202	2.3%
	Total	8965	100%
	Total need	3110	34.7%
	Need met	2301	74.0%

Table 3.2 – Paying for social care in 2016 and 2013

	2016		2013	
	Frequency	Percent	Frequency	Percent
Who pays for social care? The government does	843	18.1%	1029	44.7%
Partly the government and partly me / my family	927	19.9%	710	30.9%
I do / my family does	1829	39.2%	365	15.9%
I am not sure	388	8.3%	102	4.4%
No data	675	14.5%	95	4.1%
Total	4662	100.0%	2301	100.0%

Table 3.3 Practical support needs³

	Frequency	Percent
What sort of practical tasks do you NEED support with? Getting up in the morning	2072	37.5%
Going to bed	1834	33.2%
Washing/bathing/personal care	2781	50.3%
Meals/eating	2224	40.2%
Cooking	3730	67.5%
Getting out of the house	3541	64.0%
Shopping	4096	74.1%
Cleaning/laundry	4107	74.3%
Other	1151	20.8%
Not sure	129	2.3%

³ Percentage calculated out of respondents identifying a need in question 5

Table 3.4 Practical support receiving⁴

	Frequency	Percent
	Getting up in the morning	1951
Going to bed	1788	32.3%
Washing/bathing/personal care	2565	46.4%
Meals/eating	2180	39.4%
Cooking	3378	61.1%
Getting out of the house	3244	58.7%
Shopping	3713	67.2%
Cleaning/laundry	3698	66.9%
Other	994	18.0%
Not sure	126	2.3%

Table 3.5 – Social care plan or review offered by need met for social care support

	In the past 12 months, have you been offered a care plan and/or care plan review for your social care?					
	Yes, I have been offered a care plan	Yes, I have been offered a care plan review	No	I am not sure	No answer	Total
Yes, I have received all the support I needed	433 74.7%	249 71.1%	2128 60.6%	138 59.5%	479 56.2%	3427 62.0%
Yes, I have received some support but not enough	126 21.7%	88 25.1%	821 23.4%	66 28.4%	133 15.6%	1234 22.3%
No, but I needed to	7 1.2%	6 1.7%	373 10.6%	6 2.6%	100 11.7%	492 8.9%
I am not sure	7 1.2%	- -	101 2.9%	15 6.5%	18 2.1%	142 2.6%
No answer	7 1.2%	6 1.7%	91 2.6%	7 3.0%	123 14.4%	234 4.2%
Total	580 100.0%	350 100.0%	3514 100.0%	232 100.0%	853 100.0%	5529 100.0%
Need met	76.5%	72.6%	64.1%	65.7%	67.3%	66.5%

⁴ Percentage calculated out of respondents identifying a need to question 5

Table 3.6 – Access to social care support by age

	How old are you?							Total	
	18-29	30-39	40-49	50-59	60-69	70-79	80 or over		
In the past 12 months, have you received social care support?	Yes, I have received all the support I needed	25 11.4%	245 25.3%	612 31.8%	1000 39.6%	1005 45.6%	412 45.4%	129 50.6%	3428 38.1%
	Yes, I have received some support but not enough	32 14.5%	110 11.4%	267 13.9%	407 16.1%	280 12.7%	102 11.2%	35 13.7%	1233 13.7%
	No, and I have not needed to	127 57.7%	540 55.7%	852 44.3%	897 35.5%	713 32.3%	290 31.9%	59 23.1%	3478 38.6%
	No, but I needed to	21 9.5%	52 5.4%	121 6.3%	135 5.3%	104 4.7%	47 5.2%	11 4.3%	491 5.5%
	I am not sure	11 5.0%	14 1.4%	32 1.7%	43 1.7%	24 1.1%	18 2.0%	- -	143 1.6%
	No answer	- -	8 .8%	38 2.0%	44 1.7%	79 3.6%	39 4.3%	20 7.8%	232 2.6%
	Total	220 100.0%	969 100.0%	1922 100.0%	2526 100.0%	2205 100.0%	908 100.0%	255 100.0%	9005 100.0%
	Total need	35.5%	42.0%	52.0%	61.0%	63.0%	61.8%	68.6%	
	Need met	32.1%	60.2%	61.2%	64.9%	72.4%	73.4%	73.7%	

Table 3.7 – Need met for social care support by who pays

	Who pays for your social care? For example this could be paid for by the government e.g. 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	No answer	Total
In the past 12 months, have you received social care support?						
Yes, I have received all the support I needed	662 74.2%	1312 61.8%	669 66.8%	259 51.4%	525 52.1%	3427 62.0%
Yes, I have received some support but not enough	181 20.3%	518 24.4%	258 25.8%	128 25.4%	150 14.9%	1235 22.3%
No, but I needed to	21 2.4%	213 10.0%	35 3.5%	60 11.9%	163 16.2%	492 8.9%
I am not sure	9 1.0%	40 1.9%	21 2.1%	40 7.9%	32 3.2%	142 2.6%
No answer	19 2.1%	40 1.9%	18 1.8%	17 3.4%	138 13.7%	232 4.2%
Total	892 100.0%	2123 100.0%	1001 100.0%	504 100.0%	1008 100.0%	5528 100.0%
Need met	76.6%	64.2%	69.5%	57.9%	62.6%	

Table 3.8 – Access to social care by feelings about household income

	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	No answer	Total	
In the past 12 months, have you received social care support?	Yes, I have received all the support I needed	226 32.4%	1233 39.2%	1427 40.1%	355 33.4%	67 27.1%	119 40.8%	3427 38.0%
	Yes, I have received some support but not enough	28 4.0%	258 8.2%	588 16.5%	249 23.4%	74 30.0%	36 12.3%	1233 13.7%
	No, and I have not needed to	401 57.4%	1477 46.9%	1199 33.7%	284 26.7%	56 22.7%	63 21.6%	3480 38.6%
	No, but I needed to	23 3.3%	90 2.9%	211 5.9%	119 11.2%	32 13.0%	17 5.8%	492 5.5%
	I am not sure	8 1.1%	19 .6%	62 1.7%	35 3.3%	12 4.9%	7 2.4%	143 1.6%
	No answer	12 1.7%	71 2.3%	75 2.1%	21 2.0%	6 2.4%	50 17.1%	235 2.6%
	Total	698 100.0%	3148 100.0%	3562 100.0%	1063 100.0%	247 100.0%	292 100.0%	9010 100.0%
	Total need	39.7%	50.2%	62.5%	68.0%	70.0%	58.9%	
	Need met	81.6%	78.0%	64.1%	49.1%	38.7%	69.2%	

Table 3.9 – Where received care and support from

		Frequency	Percent
In the past 12 months, have you received care and support in relation to your MS for practical tasks from any of the following?	Your local council (or Trust in Northern Ireland) or social services	1133	22.2%
	A charity or voluntary sector organisation	411	8.1%
	Friends or family (unpaid)	4344	85.2%
	An occupational therapy service	1127	22.1%
	A private home care company	595	11.7%
	A private individual e.g. cleaner or cook	1287	25.2%
	A care home or nursing home	176	3.5%
	Other	315	6.2%
	I am not sure	83	1.6%
People only receiving care from family and friends - n =1974 (35.7% of those with a need)			

Table 3.10 – Access to social care of respondents who need support with Activities of Daily Living (ADLs – essential support)

		Frequency	Percent
In the past 12 months, have you received social care support?	Yes, I have received all the support I needed	2285	65.5%
	Yes, I have received some support but not enough	832	23.9%
	No, but I needed to	241	6.9%
	I am not sure	59	1.7%
	No answer	69	2.0%
	Total	3486	100.0%
	Need met	2285	68.0%

Table 3.11 – Age of respondents who need support with ADLs (essential support)

		Frequency	Percent
How old are you?	18-29	42	1.2%
	30-39	226	6.5%
	40-49	613	17.6%
	50-59	1037	29.8%
	60-69	1023	29.4%
	70-79	417	12.0%
	80 or over	127	3.6%
	Total	3486	100.0%

Table 3.12 – Type of MS of respondents who need support with ADLs (essential support)

	Frequency	Percent
What type of MS do you have?	Relapsing remitting MS	779 22.4%
	Secondary progressive MS with relapses	628 18.0%
	Secondary progressive MS without relapses	1014 29.1%
	Primary progressive MS	738 21.2%
	I don't know	235 6.8%
	No answer	91 2.6%
	Total	3486 100.0%

Table 3.13 – Time since diagnosis of respondents who need support with ADLs (essential support)

	Frequency	Percent
How long ago were you diagnosed as having Multiple Sclerosis by your neurologist?	Less than 12 months ago	29 0.8%
	1-5 years ago	246 7.1%
	Between 5-10 years ago	497 14.3%
	More than 10 years ago	2581 74.1%
	I don't know	11 0.3%
	No answer	121 3.5%
	Total	3486 100.0%

Table 3.14 – Who pays for social care for respondents who need support with ADLs (essential support)

	Frequency	Percent
Who pays for your social care?	The government does	724 20.8%
	I do/my family does	1256 36.0%
	Partly the government and partly me/my family	758 21.8%
	I am not sure	300 8.6%
	No answer	448 12.8%
	Total	3486 100.0%

Table 3.15 – Feelings about income for respondents who need support with ADLs (essential support)

		Frequency	Percent
Which would you say comes closest to your feelings about your current household income?	Living really comfortably on current income	159	4.6%
	Living comfortably on current income	1020	29.3%
	Neither comfortable nor struggling on current income	1532	43.9%
	Struggling on current income	515	14.8%
	Really struggling on current income	124	3.5%
	No answer	136	3.9%
	Total	3486	100.0%

Table 3.16 – Social care plan or review offered for respondents who need support with ADLs (essential support)

		Frequency	Percent
In the past 12 months, have you been offered a care plan and/or care plan review for your social care?	Yes, I have been offered a care plan	517	14.8%
	Yes, I have been offered a care plan review	319	9.2%
	No	2040	58.5%
	I am not sure	170	4.9%
	No answer	439	12.6%
	Total	3486	100.0%

Table 3.17 – Access to social care for respondents who only need support with Instrumental Activities of Daily Living (IADLs)

		Frequency	Percent
In the past 12 months, have you received social care support?	Yes, I have received all the support I needed	952	59.7%
	Yes, I have received some support but not enough	368	23.0%
	No, but I needed to	179	11.2%
	I am not sure	53	3.3%
	No answer	43	2.7%
	Total	1595	100.0%
	Need met	952	63.5%

Table 3.18 - Age of respondents who only need support with IADLs

	Frequency	Percent
How old are you?		
18-29	28	1.8%
30-39	160	10.0%
40-49	361	22.6%
50-59	489	30.7%
60-69	360	22.5%
70-79	153	9.6%
80 or over	45	2.8%
Total	1595	100.0%

Table 3.19 – Type of MS of respondents who only need support with IADLs

	Frequency	Percent
What type of MS do you have?		
Relapsing remitting MS	635	39.8%
Secondary progressive MS with relapses	230	14.4%
Secondary progressive MS without relapses	332	20.8%
Primary progressive MS	238	14.9%
I don't know	127	8.0%
No answer	33	2.0%
Total	1595	100.0%

Table 3.20 – Time since diagnosis of respondents who only need support with IADLs

	Frequency	Percent
How long ago were you diagnosed as having Multiple Sclerosis by your neurologist?		
Less than 12 months ago	25	1.5%
1-5 years ago	193	12.1%
Between 5-10 years ago	290	18.2%
More than 10 years ago	1043	65.4%
I don't know	-	-
No answer	42	2.6%
Total	1595	100.0%

Table 3.21 – Who pays for social care for respondents who only need support with IADLs

		Frequency	Percent
Who pays for your social care?	The government does	138	8.7%
	I do/my family does	800	50.1%
	Partly the government and partly me/my family	227	14.2%
	I am not sure	172	10.8%
	No answer	258	16.2%
	Total	1595	100.0%

Table 3.22 – Feelings about income for respondents who only need support with IADLs

		Frequency	Percent
Which would you say comes closest to your feelings about your current household income?	Living really comfortably on current income	95	6.0%
	Living comfortably on current income	519	32.6%
	Neither comfortable nor struggling on current income	669	41.9%
	Struggling on current income	207	13.0%
	Really struggling on current income	58	3.6%
	No answer	46	2.9%
	Total	1595	100.0%

Table 3.23 - Social care plan or review offered for respondents who only need support with IADLs

		Frequency	Percent
In the past 12 months, have you been offered a care plan and/or care plan review for your social care?	Yes, I have been offered a care plan	56	3.5%
	Yes, I have been offered a care plan review	26	1.6%
	No	1294	81.1%
	I am not sure	55	3.5%
	No answer	164	10.3%
	Total	1595	100.0%

Appendices:

Social care and the MS community in England: care and support analysis of the 2016 My MS My Needs survey

Table 3.24 – Practical tasks need support with by age

	What sort of practical tasks do you NEED support with?										
	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	Total
18-29	14 16.6%	- -	28 33.3%	18 20.8%	57 66.7%	50 58.3%	50 58.5%	50 58.5%	10 12.2%	18 21.1%	85
30-39	80 20.4%	54 13.8%	169 43.2%	132 33.6%	286 72.9%	230 58.7%	298 75.9%	295 75.0%	131 33.5%	10 2.6%	393
40-49	338 33.7%	257 25.7%	466 46.6%	402 40.2%	720 71.9%	599 59.8%	781 78.0%	784 78.2%	244 24.4%	40 4.0%	1002
50-59	595 38.6%	518 33.6%	804 52.1%	693 44.9%	1133 73.4%	1074 69.6%	1236 80.1%	1234 80.0%	359 23.3%	26 1.7%	1543
60-69	665 47.7%	630 45.2%	853 61.2%	665 47.7%	1050 75.3%	1031 74.0%	1145 82.2%	1143 82.0%	288 20.7%	21 1.5%	1393
70-79	290 50.4%	285 49.6%	350 60.8%	250 43.5%	390 67.8%	423 73.6%	451 78.4%	466 81.0%	97 16.9%	10 1.8%	575
80 or over	90 52.1%	90 51.8%	111 64.1%	64 36.8%	94 54.1%	134 77.4%	136 78.6%	137 78.9%	21 12.2%	- -	173
Total	2072	1834	2781	2224	3730	3541	4096	4107	1151	129	5164

Table 3.25 – Need met for social care for respondents only receiving support from family and friends

		Frequency	Percent
In the past 12 months, have you received social care support?	Yes, I have received all the support I needed	1237	62.7%
	Yes, I have received some support but not enough	423	21.4%
	No, but I needed to	213	10.8%
	I am not sure	42	2.2%
	No answer	59	3.0%
	Total	1974	100.0%
	Need met	1237	62.7%

Table 3.26 – Who pays for social care by whether a social care plan or review offered

	In the past 12 months, have you been offered a care plan and/or care plan review for your social care?					
	Yes, I have been offered a care plan	Yes, I have been offered a care plan review	No	I am not sure	No answer	Total
The government does	253 43.7%	133 38.0%	325 9.3%	57 24.5%	124 14.6%	892 16.1%
I do/my family does	91 15.7%	48 13.7%	1737 49.4%	58 24.9%	189 22.2%	2123 38.4%
Partly the government and partly me/my family	175 30.2%	139 39.7%	505 14.4%	50 21.5%	130 15.3%	999 18.1%
I am not sure	20 3.5%	8 2.3%	378 10.8%	50 21.5%	49 5.8%	505 9.1%
No answer	40 6.9%	22 6.3%	568 16.2%	18 7.7%	360 42.3%	1008 18.2%
Total	579 100.0%	350 100.0%	3513 100.0%	233 100.0%	852 100.0%	5527 100.0%

Table 3.27 – Need met for social care support by type of MS

	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	No answer	Total	
In the past 12 months, have you received social care support?	Yes, I have received all the support I needed	920 57.0%	543 60.4%	947 67.0%	688 66.4%	254 63.0%	76 46.3%	3428 62.0%
	Yes, I have received some support but not enough	375 23.2%	239 26.6%	297 21.0%	212 20.5%	70 17.4%	41 25.0%	1234 22.3%
	No, but I needed to	194 12.0%	69 7.7%	98 6.9%	79 7.6%	40 9.9%	12 7.3%	492 8.9%
	I am not sure	61 3.8%	19 2.1%	20 1.4%	22 2.1%	13 3.2%	7 4.3%	142 2.6%
	No answer	63 3.9%	29 3.2%	52 3.7%	35 3.4%	26 6.5%	28 17.1%	233 4.2%
	Total	1613 100.0%	899 100.0%	1414 100.0%	1036 100.0%	403 100.0%	164 100.0%	5529 100.0%
	Need met	61.8%	63.8%	70.6%	70.3%	69.8%	58.9%	

Table 3.28 – Offered a care plan or care plan review (excluding respondents who ticked 'No, and I have not needed to' for question 5)

		Frequency	Percent
In the past 12 months, have you been offered a care plan and/or care plan review for your social care?	Yes, I have been offered a care plan	580	10.4%
	Yes, I have been offered a care plan review	350	6.3%
	No	3514	63.6%
	I am not sure	232	4.2%
	No answer	853	15.4%
	Total	5529	100.0%

Table 3.29 – Feelings about household income (excluding respondents who ticked 'No, and I have not needed to' for question 5)

		Frequency	Percent
Which would you say comes closest to your feelings about your current household income?	Living really comfortably on current income	297	5.4%
	Living comfortably on current income	1670	30.2%
	Neither comfortable nor struggling on current income	2363	42.7%
	Struggling on current income	779	14.1%
	Really struggling on current income	191	3.5%
	No answer	229	4.1%
	Total	5529	100.0%

4. Scotland Tables

Table 4.1a – Need and access to social care support in 2016

		Frequency	Percent
In the past 12 months, have you received social care support?	Yes, I have received all the support I needed	338	36.0%
	Yes, I have received some support but not enough	130	13.9%
	No, and I have not needed to	391	41.6%
	No, but I needed to	45	4.8%
	I am not sure	12	1.3%
	No answer	22	2.3%
	Total	939	100.0%
	Total need	514	54.7%
	Need met	338	65.8%

Table 4.1b Need and access to social care support in 2013

		Frequency	Percent
In the past 12 months, have you received social care support?	Yes	242	27.8%
	No, but I needed to	77	8.9%
	No, and I have not needed to	492	56.6%
	No answer	23	2.6%
	I am not sure	36	4.1%
	Total	870	100.0%
	Total need	319	36.7%
	Need met	242	75.9%

Table 4.2 – Paying for social care in 2016 and 2013

Who pays for your social care?	2016		2013	
	Frequency	Percent	Frequency	Percent
The government does	88	18.7%	102	42.1%
I do/my family does	171	36.5%	36	14.9%
Partly the government and partly me/my family	96	20.4%	76	31.4%
I am not sure	41	8.8%	15	6.2%
No answer	73	15.6%	13	5.4%
Total	469	100.0%	242	100.0%

Table 4.3 – Practical support needs⁵

	Frequency	Percent
Getting up in the morning	192	37.3%
Going to bed	184	35.7%
Washing/bathing/personal care	253	49.2%
Meals/eating	205	39.8%
Cooking	366	71.1%
Getting out of the house	345	67.1%
Shopping	402	78.2%
Cleaning/laundry	397	77.2%
Other	109	21.1%
Not sure	18	3.5%

⁵ Percentage calculated out of respondents identifying a need in question 5

Table 4.4 – Practical support receiving⁶

	Frequency	Percent
Getting up in the morning	180	35.0%
Going to bed	175	34.0%
Washing/bathing/personal care	229	44.5%
Meals/eating	202	39.4%
Cooking	318	61.8%
Getting out of the house	311	60.5%
Shopping	360	70.1%
Cleaning/laundry	359	69.8%
Other	86	16.6%
Not sure	18	3.5%

Table 4.5 – Where received care and support from

	Frequencies	Percent
Your local council (or Trust in Northern Ireland) or social services	127	25.0%
A charity or voluntary sector organisation	57	11.2%
Friends or family (unpaid)	457	89.7%
An occupational therapy service	110	21.6%
A private home care company	51	10.1%
A private individual e.g. cleaner or cook	127	24.9%
A care home or nursing home	16	3.2%
Other	30	5.8%
I am not sure	-	-

People only receiving care from family and friends - n = 199 (38.7% of those with a need)

⁶ Percentage calculated out of respondents identifying a need in question 5

Appendices:

Social care and the MS community in England: care and support analysis of the 2016 My MS My Needs survey

Table 4.6 – Access to social care for respondents who need support with ADLs (essential support)

		Frequency	Percent
In the past 12 months, have you received social care support?	Yes, I have received all the support I needed	203	62.1%
	Yes, I have received some support but not enough	84	25.8%
	No, but I needed to	22	6.6%
	I am not sure	7	2.0%
	No answer	12	3.5%
	Total	327	100.0%
	Need met	203	65.7%

Table 4.7 – Access to social care for respondents who only need support with IADLs

		Frequency	Percent
In the past 12 months, have you received social care support?	Yes, I have received all the support I needed	114	62.5%
	Yes, I have received some support but not enough	41	22.6%
	No, but I needed to	22	11.8%
	I am not sure	-	-
	No answer	-	-
	Total	182	100.0%
	Need met	114	64.4%

Table 4.8 - Offered a care plan or care plan review (excluding respondents who ticked 'No, and I have not needed to' for question 5)

		Frequency	Percent
In the past 12 months, have you been offered a care plan and/or care plan review for your social care?	Yes, I have been offered a care plan	58	10.6%
	Yes, I have been offered a care plan review	33	6.1%
	No	343	62.6%
	I am not sure	30	5.5%
	No answer	83	15.2%
	Total	548	100.0%

Table 4.9 - Feelings about household income (excluding respondents who ticked 'No, and I have not needed to' for question 5)

		Frequency	Percent
Which would you say comes closest to your feelings about your current household income?	Living really comfortably on current income	29	5.3%
	Living comfortably on current income	160	29.2%
	Neither comfortable nor struggling on current income	245	44.7%
	Struggling on current income	69	12.6%
	Really struggling on current income	22	3.9%
	No answer	23	4.2%
	Total	548	100.0%

5. Wales Tables

Table 5.1a – Need and access to social care support in 2016

		Frequency	Percent
In the past 12 months, have you received social care support?	Yes, I have received all the support I needed	231	40.1%
	Yes, I have received some support but not enough	104	18.1%
	No, and I have not needed to	185	32.2%
	No, but I needed to	35	6.1%
	I am not sure	8	1.5%
	No answer	12	2.0%
	Total	575	100.0%
	Total need	370	64.3%
	Need met	231	62.4%

Table 5.1b - Need and access to social care support in 2013

		Frequency	Percent
In the past 12 months, have you received social care support?	Yes	122	29.4%
	No, and I have not needed to	225	54.2%
	No, but I needed to	36	8.7%
	I am not sure	20	4.8%
	No answer	12	2.9%
	Total	415	100.0%
	Total need	158	38.1%
	Need met	122	77.2%

Table 5.2 – Paying for your social care 2016 and 2013

	2016		2013	
	Frequency	Percent	Frequency	Percent
Who pays for your social care?				
The government does	49	14.6%	55	45.1%
I do/my family does	136	40.6%	11	9.0%
Partly the government and partly me/my family	69	20.7%	46	37.7%
I am not sure	43	12.9%	6	4.9%
No answer	38	11.2%	-	-
Total	335	100.0%	122	100.0%

Table 5.3 – Practical support needs⁷

	Frequency	Percent
What sort of practical tasks do you NEED support with?		
Getting up in the morning	148	40.1%
Going to bed	119	32.1%
Washing/bathing/personal care	179	48.3%
Meals/eating	154	41.6%
Cooking	264	71.4%
Getting out of the house	231	62.5%
Shopping	284	76.7%
Cleaning/laundry	277	74.9%
Other	59	16.0%
Not sure	11	3.0%

⁷ Percentage calculated out of respondents identifying a need in question 5

Table 5.4 – Practical support receiving⁸

	Frequency	Percent
Getting up in the morning	126	33.9%
Going to bed	112	30.2%
Washing/bathing/personal care	156	42.2%
Meals/eating	138	37.2%
Cooking	250	67.5%
Getting out of the house	212	57.3%
Shopping	241	65.1%
Cleaning/laundry	245	66.2%
Other	50	13.6%
Not sure	8	2.1%

Table 5.5 – Where received care and support from

	Frequency	Percent
Your local council (or Trust in Northern Ireland) or social services	105	28.7%
A charity or voluntary sector organisation	33	8.9%
Friends or family (unpaid)	314	85.8%
An occupational therapy service	93	25.3%
A private home care company	27	7.4%
A private individual e.g. cleaner or cook	80	21.9%
A care home or nursing home	5	1.3%
Other	17	4.6%
I am not sure	7	2.0%

People only receiving care from family and friends - n = 157 (42.4% of those with a need)

⁸ Percentage calculated out of respondents identifying a need in question 5

Table 5.6 – Access to social care for respondents who need support with ADLs (essential support)

		Frequency	Percent
In the past 12 months, have you received social care support?	Yes, I have received all the support I needed	154	61.0%
	Yes, I have received some support but not enough	68	27.1%
	No, but I needed to	21	8.3%
	I am not sure	6	2.4%
	No answer	-	-
	Total	253	100.0%
	Need met	154	63.3%

Table 5.7 – Access to social care for respondents who only need support with IADLs

		Frequency	Percent
In the past 12 months, have you received social care support?	Yes, I have received all the support I needed	60	56.2%
	Yes, I have received some support but not enough	32	30.3%
	No, but I needed to	11	10.6%
	I am not sure	-	-
	No answer	-	-
	Total	106	100.0%
	Need met	60	57.9%

Table 5.8 – Offered a care plan or care plan review (excluding respondents who ticked 'No, and I have not needed to' for question 5)

		Frequency	Percent
In the past 12 months, have you been offered a care plan and/or care plan review for your social care?	Yes, I have been offered a care plan	42	10.8%
	Yes, I have been offered a care plan review	14	3.7%
	No	265	67.9%
	I am not sure	18	4.6%
	No answer	51	13.0%
	Total	390	100.0%

Table 5.9 - Feelings about household income (excluding respondents who ticked 'No, and I have not needed to' for question 5)

		Frequency	Percent
Which would you say comes closest to your feelings about your current household income?	Living really comfortably on current income	24	6.0%
	Living comfortably on current income	107	27.5%
	Neither comfortable nor struggling on current income	158	40.5%
	Struggling on current income	65	16.7%
	Really struggling on current income	18	4.5%
	No answer	18	4.7%
	Total	390	100.0%

6. Northern Ireland Tables

Table 6.1a – Need and access to social care support in 2016

		Frequency	Percent
In the past 12 months, have you received social care support?	Yes, I have received all the support I needed	146	39.8%
	Yes, I have received some support but not enough	56	15.3%
	No, and I have not needed to	122	33.4%
	No, but I needed to	23	6.2%
	I am not sure	12	3.3%
	No answer	7	1.9%
	Total	366	100.0%
	Total need	225	61.4%
	Need met	146	64.9%

Table 6.1b Need and access to social care support in 2013

		Frequency	Percent
In the past 12 months, have you received social care support?	Yes, I have received all the support I needed	87	31.1%
	No, and I have not needed to	148	52.9%
	No, but I needed to	27	9.6%
	I am not sure	15	5.4%
	No answer	-	-
	Total	280	100.0%
	Total need	114	40.7%
	Need met	87	76.3%

Table 6.2 – Paying for social care 2016 and 2013

	2016		2013	
	Frequency	Percent	Frequency	Percent
Who pays for your social care?				
The government does	58	28.8%	62	71.3%
I do/my family does	52	25.7%	-	-
Partly the government and partly me/my family	36	18.0%	13	14.9%
I am not sure	36	18.0%	-	-
No answer	19	9.4%	6	6.9%
Total	202	100.0%	87	100.0%

Table 6.3 – Practical support needs⁹

	Frequency	Percent
What sort of practical tasks do you NEED support with?		
Getting up in the morning	92	40.7%
Going to bed	71	31.6%
Washing/bathing/personal care	124	55.0%
Meals/eating	80	35.7%
Cooking	157	70.0%
Getting out of the house	134	59.8%
Shopping	172	76.6%
Cleaning/laundry	184	81.9%
Other	33	14.7%
Not sure	-	-

⁹ Percentage calculated out of respondents identifying a need in question 5

Table 6.4 – Practical support receiving¹⁰

		Frequency	Percent
What sort of practical tasks do you RECEIVE support with?	Getting up in the morning	87	38.6%
	Going to bed	67	29.6%
	Washing/bathing/personal care	97	43.2%
	Meals/eating	68	30.4%
	Cooking	134	59.4%
	Getting out of the house	114	50.4%
	Shopping	136	60.5%
	Cleaning/laundry	142	63.1%
	Other	31	14.0%
	Not sure	6	2.8%

Table 6.5 – Where received care and support from

		Frequency	Percent
In the past 12 months, have you received care and support in relation to your MS for practical tasks from any of the following?	Your local council (or Trust in Northern Ireland) or social services	58	26.1%
	A charity or voluntary sector organisation	23	10.6%
	Friends or family (unpaid)	183	82.5%
	An occupational therapy service	45	20.5%
	A private home care company	15	6.7%
	A private individual e.g. cleaner or cook	61	27.4%
	A care home or nursing home	8	3.5%
	Other	10	4.3%
	I am not sure	5	2.5%
People only receiving care from family and friends - n = 81 (36.0% of those with a need)			

¹⁰ Percentage calculated out of respondents identifying a need in question 5

Table 6.6 – Access to social care for respondents who need support with ADLs (essential support)

		Frequency	Percent
In the past 12 months, have you received social care support?	Yes, I have received all the support I needed	87	60.3%
	Yes, I have received some support but not enough	39	27.1%
	No, but I needed to	13	8.7%
	I am not sure	-	-
	No answer	-	-
	Total	145	100.0%
	Need met	87	62.8%

Table 6.7 – Access to social care for respondents who only need support with IADLs

		Frequency	Percent
In the past 12 months, have you received social care support?	Yes, I have received all the support I needed	49	61.3%
	Yes, I have received some support but not enough	15	18.7%
	No, but I needed to	8	10.3%
	I am not sure	7	8.5%
	No answer	-	-
	Total	79	100.0%
	need met	49	67.9%

Table 6.8 – Offered a care plan or care plan review

		Frequency	Percent
In the past 12 months, have you been offered a care plan and/or care plan review for your social care?	Yes, I have been offered a care plan	35	9.6%
	Yes, I have been offered a care plan review	13	3.7%
	No	227	62.0%
	I am not sure	14	3.9%
	No answer	76	20.8%
	Total	366	100.0%

Appendices:

Social care and the MS community in England: care and support analysis of the 2016 My MS My Needs survey

Table 6.9 - Offered a care plan or care plan review (excluding respondents who ticked 'No, and I have not needed to' for question 5)

		Frequency	Percent
In the past 12 months, have you been offered a care plan and/or care plan review for your social care?	Yes, I have been offered a care plan	35	14.4%
	Yes, I have been offered a care plan review	13	5.2%
	No	153	62.7%
	I am not sure	11	4.4%
	No answer	32	13.3%
	Total	244	100.0%

Table 6.10 - Feelings about household income (excluding respondents who ticked 'No, and I have not needed to' for question 5)

		Frequency	Percent
Which would you say comes closest to your feelings about your current household income?	Living really comfortably on current income	11	4.4%
	Living comfortably on current income	65	26.6%
	Neither comfortable nor struggling on current income	104	42.7%
	Struggling on current income	40	16.4%
	Really struggling on current income	5	2.2%
	No answer	19	7.7%
	Total	244	100.0%

Appendix 2 - 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

[ROUTING: If no go to Q22]

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

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 fumerate)
- 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 3 - Questionnaire cover letter¹¹



[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 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.

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

¹¹ Please note that the questionnaire cover letter above contains the old MS Society logo as was released prior to rebrand.

