Appendix 1 – data tables for UK

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'.

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. 45% 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**	
Collection type	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**	
Are you male or female?	Female	6739	277	692	425	8132
		74.8%	75.5%	73.7%	73.9%	74.7%
	Male	2269	90	247	150	2756
		25.2%	24.5%	26.3%	26.1%	25.3%
	Total	9008	366	939	575	10888
		100.0%	100.0%	100.0%	100.0%	100.0%

Table 1.3 - Age

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

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 2.1 - Use of DMTs among those who could potentially benefit[1]

	2016		2013	
	Frequency	**Percent**	**Frequency**	**Percent**
Not taking a DMT	2664	43.7%	2949	60.1%
Taking a DMT	3433	56.3%	1960	39.9%
Total	6097	100.0%	4909	100.0%

Table 2.2 - Use of DMTs by combination of access to MS nurses, neurologists or information about drugs

	2016			2013		
	Not taking DMT	**Taking DMT**	**Total**	**Not taking DMT**	**Taking DMT**	**Total**
Access to no 'services'	532 88.7%	68 11.3%	600 100.0%	593 92.7%	47 7.3%	640 100.0%
Access to one 'service'	827 70.2%	351 29.8%	1178 100.0%	778 80.7%	186 19.3%	964 100.0%
Access to two 'services'	867 40.8%	1257 59.2%	2124 100.0%	855 55.2%	693 44.8%	1548 100.0%
Access to three 'services'	380 18.2%	1710 81.8%	2090 100.0%	438 31.3%	962 68.7%	1400 100.0%
Estimated could potentially benefit from DMTs	2606 43.5%	3386 56.5%	5992 100.0%	2664 58.5%	1888 41.5%	4552 100.0%

Table 2.3 - Use of DMTs by time since diagnosis (2016 data)

		2016		
		Not taking a DMT	**Taking a DMT**	**Total**
Time since diagnosis	Less than 12 months ago	45 26.3%	126 73.7%	171 100.0%
	1-5 years ago	278 24.3%	868 75.7%	1146 100.0%
	Between 5-10 years ago	451 33.3%	905 66.7%	1356 100.0%
	More than 10 years ago	1810 55.7%	1438 44.3%	3248 100.0%
	I don't know	5 55.6%	4 44.4%	9 100.0%
	Total	2589 43.7%	3341 56.3%	5930 100.0%

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[1] 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 2.4 - Need and access to an MS specialist nurse

		2016	2013
In the past 12 months, have you seen an MS specialist nurse in relation to your MS?	Yes	7320 68.3%	6194 59.8%
	No, and I have not needed to	2096 19.5%	2780 26.9%
	No, but I needed to	1186 11.1%	1278 12.3%
	I am not sure	120 1.1%	99 1.0%
	Total	10721 100.0%	10351 100.0%
	Total need	79.3%	72.2%
	Need met	86.1%	82.9%

Table 2.5 - Need and access to a neurologist

		2016	2013
In the past 12 months, have you seen a neurologist in relation to your MS?	Yes	6771 63.2%	5661 54.7%
	No, and I have not needed to	2672 25.0%	3400 32.9%
	No, but I needed to	1122 10.5%	1154 11.2%
	I am not sure	144 1.3%	131 12.7%
	Total	10709 100.0%	10346 100.0%
	Total need	73.7%	65.9%
	Need met	85.7%	83.1%

Table 2.6 - Need and access to a specialist about continence advice

		2016	2013
In the past 12 months, have you seen a specialist about continence advice in relation to your MS?	Yes	3834 36.0%	3253 31.4%
	No, and I have not needed support	5256 49.3%	5535 53.4%
	No, but I needed support	1417 13.3%	1360 13.1%
	I am not sure	152 1.4%	216 21.%
	Total	10659 100.0%	10364 100.0%
	Total need	49.3%	44.5%
	Need met	73.0%	70.5%

Table 2.7 - Access to support to keep physically active (2016 data)

		Frequency	Percent
Have you received support so that you can keep physically active?	Yes, from the NHS	878	8.3%
	Yes, from my local council (or Trust in Northern Ireland)	309	2.9%
	Yes, from a charity or voluntary organisation	1091	10.3%
	Yes, from somewhere else	1015	9.6%
	No, and I have not needed to	4505	42.6%
	No, but I needed to	2700	25.6%
	I am not sure	374	3.5%
	Total[2]	10871	102.9%
	Percentage of respondents who received support		28.3%

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[2] Percentages will sum to greater than 100% as multiple answers were possible

Table 2.8 - Access to support to keep physically active (2013 data)

		Frequency	**Percent**
Have you received support so that you can keep physically active?	Yes	2653	25.8%
	No, and I have not needed to	4339	42.2%
	No, but I needed to	2992	29.1%
	I am not sure	293	28.5%
	Total	10277	100.0%
	Total need		54.9%
	Need met		47.0%

Table 2.9 - Access to a physiotherapist (2016 data)

		Frequency	**Percent**
In the past 12 months, have you seen a physiotherapist in relation to your MS?	Yes, from the NHS	3384	31.7%
	Yes, privately	724	6.8%
	Yes, from a charity or voluntary organisation	713	6.7%
	Yes, from somewhere else	131	1.2%
	No, and I have not needed to	4101	38.5%
	No, but I needed to	1772	16.6%
	I am not sure	210	2.0%
	Total[3]	11035	103.5%
	Percentage of respondents who received support		42.9%

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[3] Percentages will sum to greater than 100% as multiple answers were possible

Table 2.10 - Access to a physiotherapist (2013 data)

		Frequency	Percent
Have you seen a physiotherapist in relation to your MS?	Yes	4541	43.8%
	No, and I have not needed to	3688	35.6%
	No, but I needed to	1960	18.9%
	I am not sure	182	17.5%
	Total	10371	100.0%
	Total need		62.7%
	Need met		69.9%

Table 2.11 - Access to support for mood or emotional issues[4] (2016 data)

		Frequency	Percent
Have you received sufficient support for mood or emotional issues?	Yes, from the NHS	1727	16.2%
	Yes, from a charity or voluntary organisation	316	3.0%
	Yes, from a private company or individual	212	2.0%
	Yes, from somewhere else	346	3.2%
	No, and I have not needed support	5677	53.4%
	No, but I needed support/more support	2236	21.0%
	I am not sure	335	3.1%
	Total	10848	102.0%
	Percentage of respondents who received support		22.5%

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

Table 2.12 - Key contact for health care and support (2016 data)

		Frequency	Percent
Who is the key contact for any health care or support in relation to your MS?	My GP	1964	21.0%
	My MS nurse	4254	45.5%
	My neurologist	687	7.3%
	My carer / a member of my family	1347	14.4%
	No one	470	5.0%
	I am not sure	631	6.7%
	Total	9353	100.0%
	Multiple responses given	1257	

Table 2.13 – Key contact for health care and support by information about available MS drugs (2016 data)

		Key contact							Total
		GP	MS Nurse	Neurologist	Carer/ a member of my family	No one	I am not sure	Multiple responses given	
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	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 2.14 - Care plan and care plan review (2016 data)

		Frequency	Percent
In the past 12 months, have you been offered a care plan and/or care plan review for your health care? [5]	Yes, I have been offered a care plan	722	6.8%
	Yes, I have been offered a care plan review	548	5.2%
	No	8711	82.6%
	I am not sure	567	5.4%
	Total	10548	100.0%

Table 2.15 – Need and access to social care support (2016 data)

		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%

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[5] 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'.

Table 2.16 – Need and access to social care support (2013 data)

		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 2.17 – Access to social care support by age (2016 data)

		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	332	766	1196	1181	486	142	4142
		13.9%	26.5%	32.0%	39.3%	45.7%	46.5%	49.8%	38.0%
	Yes, I have received some support but not enough	46	149	344	498	332	113	43	1525
		16.4%	11.9%	14.4%	16.4%	12.9%	10.8%	15.1%	14.0%
	No, and I have not needed to	152	683	1049	1076	824	326	66	4176
		54.3%	54.5%	43.8%	35.3%	31.9%	31.2%	23.2%	38.4%
	No, but I needed to	25	63	147	170	126	53	11	595
		8.9%	5.0%	6.1%	5.6%	4.9%	5.1%	3.9%	5.5%
	I am not sure	11	19	40	51	33	22	-	177
		3.9%	1.5%	1.7%	1.7%	1.3%	2.1%	-	1.6%
	No answer	7	8	49	54	86	45	22	271
		2.5%	.6%	2.0%	1.8%	3.3%	4.3%	7.7%	2.5%
	Total	280	1254	2395	3045	2582	1045	285	10886
		100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	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 2.18 – Offered a care plan or care plan review (excluding respondents who ticked 'No, and I have not needed to' for question 5) (2016 data)

		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 2.19 – 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 2.20 – Need met for social care support by who pays (2016 data)

		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%	

Table 2.21 – Where received care and support (2016 data)

		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	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%
People only receiving care from family and friends - n = 2411 (38.5% of those with a need)			

Table 2.22 – Where received care and support (2013 data)

		Frequency	Percent
Do you have a friend or family member who provides unpaid care, support or assistance to you in relation to your MS?	Yes	7348	70.6%
	No	2839	27.3%
	I am not sure	224	2.2%
	Total	10411	100.0%

Table 2.23 – Access to social care by feelings about household income (2016 data)

		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%	

Table 2.24 - Employment status of respondents under 60 (2016 data)

		Frequency	Percent
Are you currently in paid employment?	Yes, employed / self-employed full time	1659	24.5%
	Yes, employed / self-employed part time	1341	19.8%
	No, looking for work	782	11.5%
	No, not looking for work	1559	23.0%
	No retired	1415	20.9%
	No, student	72	1.1%
	Total	6828	100.7%

Table 2.25 - Support finding employment for people either in work, looking for work or a student (2016 data)

		Frequency	Percent
In the past 12 months, have you received support to help you find employment?	Yes	85	1.9%
	No, and I have not needed support	1700	38.7%
	No, but I needed support	172	3.9%
	I am not sure	48	1.1%
	No answer	2392	54.4%
	Total	4397	100.0%
	Total need		5.8%
	Need met		33.0%

Table 2.26 - Support remaining in employment for people either in work, looking for work or a student (2016 data)

		Frequency	Percent
In the past 12 months, have you received support to remain in employment?	Yes	270	6.1%
	No, and I have not needed support	1453	33.0%
	No, but I needed support	208	4.7%
	I am not sure	85	1.9%
	No answer	2381	54.2%
	Total	4397	100.0%
	Total need		10.9%
	Need met		56.6%

Table 2.27 - Proportion of people receiving ESA (2016 data)

Do you currently receive Employment Support Allowance (ESA)?		
Yes	No	Total
2448 22.5%	8440 77.5%	10888 100.0%

Table 2.28 - Employment status by ESA (2016 data)

		Currently receive ESA		Total
		No	**Yes**	
Employment status	Not in employment (looking for work, not looking for work and students)	1334 48.9%	1393 51.1%	2727 100.0%
	Employed (employed/ self-employed full time and employed/ self-employed part time)	3129 97.3%	85 2.7%	3215 100.0%
	No retired	3814 80.4%	929 19.6%	4743 100.0%

Table 2.29 - Employment status by PIP (2016 data)

		Currently receive PIP		Total
		No	**Yes**	
Employment status	Yes, employed / self-employed full time	1607 93.2%	117 6.8%	1724
	Yes, employed / self-employed part time	1345 90.2%	146 9.8%	1491
	No, looking for work	678 80.5%	165 19.5%	843
	No, not looking for work	1595 88.1%	215 11.9%	1809
	No, retired	4404 92.9%	339 7.1%	4743
	No, student	66 88.0%	9 12.0%	75
	Total	9620	984	10604

Table 2.30 – Employment status by DLA (2016 data)

		Currently receive DLA		Total
		No	**Yes**	
Employment Status	Yes, employed / self-employed full time	1390 80.6%	334 19.4%	1724
	Yes, employed / self-employed part time	892 59.9%	598 40.1%	1491
	No, looking for work	296 35.1%	547 64.9%	843
	No, not looking for work	349 19.3%	1461 80.7%	1809
	No, retired	1200 25.3%	3543 74.7%	4743
	No, student	46 61.9%	29 38.1%	75
	Total	4157	6446	10604

Table 2.31 - Changes made relating to work as a result of MS

		Frequency	**Percent**
Work changes	Changed working hours	2157	22.2%
	Changed jobs or roles	1383	14.2%
	Retired early	3443	35.4%
	Left work entirely	3161	32.5%
	Changed location	766	7.9%
	Made physical changes/adaptations to my work environment	1197	12.3%
	Other	598	6.2%
	None	1295	13.3%
	Total	14001	144.1%

Table 2.32 - Left work entirely or retired early as a result of MS

Left work/retired early	**Total who answered question**
5843 60.1%	9718 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 <u>NEED</u> 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 <u>RECEIVE</u> 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 <u>social care</u>? 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 <u>find</u> 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 <u>to remain</u> 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 of 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 <u>healthcare</u>? 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

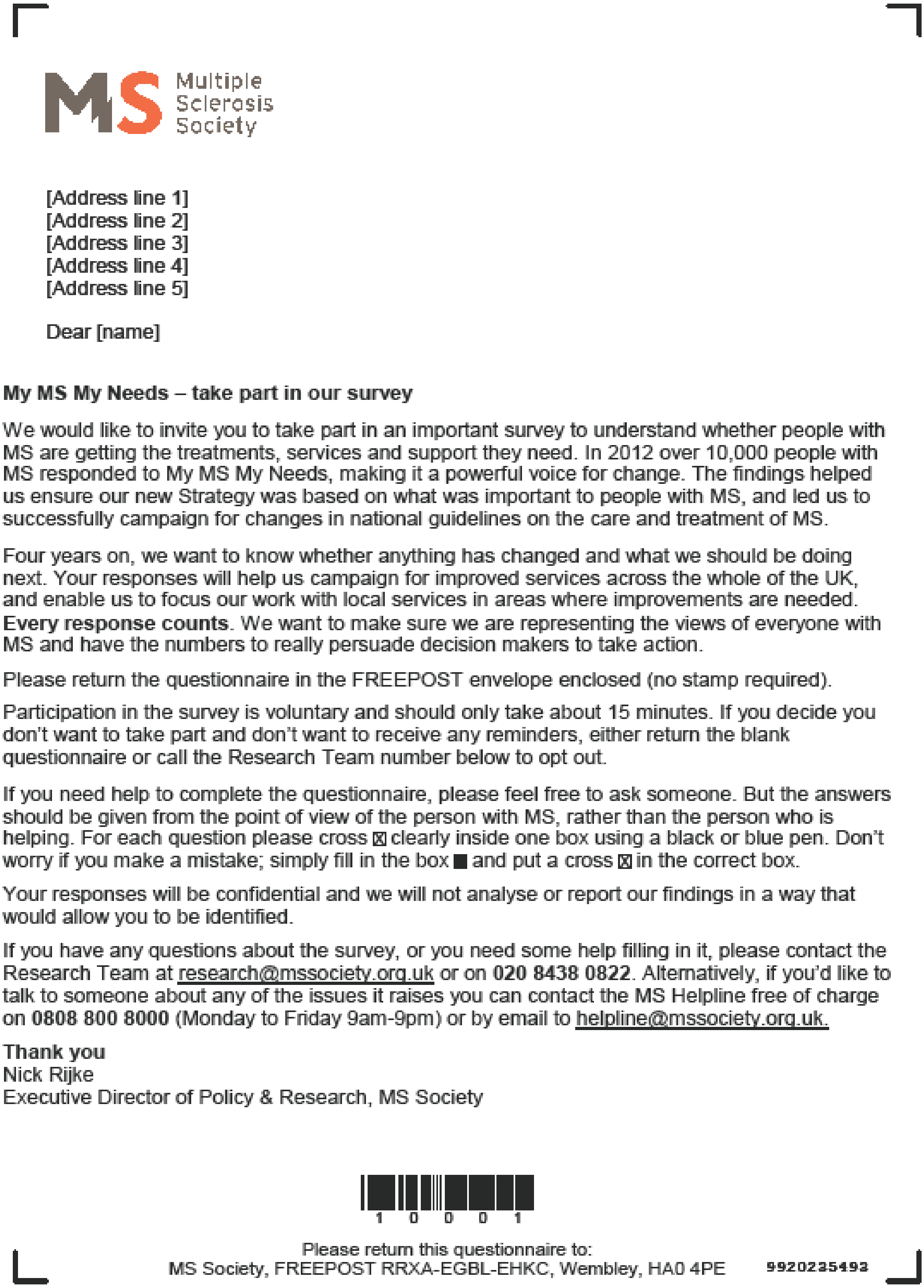
Before you go

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 letter[6]



Multiple Sclerosis Society

[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

1 0 0 0 1

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

9920235493

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