

My MS My Needs 3 – 2019 Nation specific data tables

MMMN3 nation data tables

Let's stop MS together

May 2020

1. Introduction

This report provides a selection of data tables to support the UK wide report for the My MS My Needs 3 survey.

We conducted a survey of 8,281 people across the UK with MS between March and May 2019, making this one of the largest collection of patient-reported data from the UK MS community. There are an estimated 131,000 people living with MS in the UK.

The initial survey was run in 2013 and again in 2016. 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.

In 2019, 55% of respondents completed a paper-based survey, sent out to MS Society members and upon request. 45% of respondents completed the survey through an email link, promoted via the MS Register, our channels, professional contacts and through our regional influencing teams and local network officers.

In this survey 82% of respondents were from England, 8% from Scotland, 5% from Wales, 4% from Northern Ireland and for 1% their location was unknown. 75% of respondent's women and 25% were men. The majority of respondents (51%) were aged between 45 and 64 years old, with 23% being younger than 45 and 27% being 65 years old or older.

Due to age and gender bias in our sample, the data has been weighted to be representative of the UK MS population. In the 2019 survey some questions were changed, removed or added, meaning that comparisons to 2016 or 2013 cannot always be made.

2. Note on data tables

The title of each table is directly comparable to the format in which the question was asked in the survey. Except in the case where two questions have been crossed for comparison. In these cases the title of the table is representative of the data shown.

Where the question was single answer the total sample size is denoted by 'Total' at the bottom of the table. Where respondents were able to select more than one response the total sample size is denoted at the bottom of the table by 'total respondents'. In these instances the percentages may not sum to 100%.

Where straight proportions of a single question are presented these are accompanied by the 95% confidence interval (CI). The first number is the lower and the second number is the upper confidence interval. Where there has been a cross of two question statistical significance was determined by Chi Square test and the p value (above or below 0.05) is shown in the table.

Some of the figures cited in this report are the proportion of people with a given need who said that this need was met. This is the number of people who answered 'Yes' to a specific question, divided by the number of people who answered either 'Yes' or 'No, but I needed to'.

3. Demographics

What type of MS do you have?

			Northern	
	England	Scotland	Ireland	Wales
Relapsing remitting	3,125	341	206	202
	47%	50%	69%	45%
	CI 46 - 48%	CI 46-54%	CI 64-74%	CI 40-50%
Secondary	767	72	21	66
progressive with	11%	11%	7%	15%
relapses	Cl 11-12%	CI 8-14%	CI 4-10%	CI 12-18%
Secondary	1,388	136	31	106
progressive without	21%	20%	10%	24%
relapses	CI 20-22%	CI 17-23%	CI 7-14%	CI 20-28%
Primary progressive	1,013	94	21	55
,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,	15%	14%	7%	12%
	CI 14-16%	CI 16-11%	CI 4-10%	CI 9-15%
I don't know	390	41	19	19
	6%	6%	7%	4%
	CI 5-6%	CI 4-8%	4-9%	CI 2-6%
Total	6,683	684	298	447
	100%	100%	101%	100%

What is your gender?

			Northern	
	England	Scotland	Ireland	Wales
Female	5,069	494	229	348
	75%	72%	77%	78%
	CI 74-76%	CI 68-75%	CI 72 -81%	CI 74-81%
Male	1,673	192	70	98
	25%	28%	23%	22%
	CI 24-26%	CI 24-31%	CI 19-28%	Ci 18-26%
Non-binary	6	0	0	0
	<1%	0%	0%	0%
	Cl <1% - <1%			
Prefer not to	4	3	0	2
say	<1%	<1%	0%	<1%
	Cl <1% - <1%	CI 0-1%		CI 0-1%
Total	6,752	689	299	448
	100%	100%	100%	100%

How old are you? (years)

Γ			Northern	
	England	Scotland	Ireland	Wales
16 - 24	41	4	4	6
	1%	1%	1%	1%
	CI 0 - 1%		CI 0-2%	CI 0-2%
25 - 34	401	59	51	40
	6%	8%	17%	9%
	CI 5 - 6%		CI 13-21%	CI 6-12%
35 - 44	977	118	55	56
	14%	17%	18%	12%
	CI 14 - 15%		CI 14-23%	CI 9-16%
45 - 54	1,741	191	94	130
	26%	28%	31%	29%
	CI 25 - 27%		CI 26 - 37%	CI 22-30%
55 - 64	1,673	169	62	118
	25%	24%	21%	26%
	CI 24 - 26%		CI 16-25%	CI 22-30%
65 - 74	1,328	112	26	74
	20%	16%	9%	16%
	CI 19 - 21%		CI 6-12%	CI 13-20%
75 - 84	460	29	5	20
	7%	4%	2%	4%
	CI 6- 7%		CI 0-3%	Ci 2-6%
85 +	136	9	4	5
	2%	1%	1%	1%
	Cl 2 - 2%		CI 0-2%	CI 0-2%
Prefer not to	5	2	0	0
say	<1%	<1%	0%	0%
	Cl <1% - <1%	Cl <1% - <1%		
Total	6,762	692	300	448
	100%	100%	100%	100%

How long ago where you diagnosed as having MS by your neurologist?

Γ			Northern	
	England	Scotland	Ireland	Wales
Less than 12	161	20	11	17
months	2%	3%	4%	4%
	CI 2-3%	CI 2-4%	Ci 2-6%	CI 2-6%
1-2 years	359	34	29	21
	5%	5%	10%	5%
	CI 5-6%	CI 3-7%	CI 6-13%	CI 3-7%
3-5 years	715	111	58	48
	11%	16%	19%	11%
	CI 10-11%	CI 13-19%	CI 15-24%	CI 8-13%
6-10 years	1,236	123	66	100
	18%	18%	22%	22%
	CI 17-19%	CI 15-21%	CI 17-27%	CI 18-26%
11-15 years	1,142	105	42	76
	17%	15%	14%	17%
	CI 16-18%	CI 13-18%	CI 10-18%	CI 14-21%
16-20 years	1,009	100	40	62
	15%	15%	14%	14%
	CI 14-16%	CI 12-17%	CI 10-17%	CI 11-17%
21-50 years	2,010	191	50	120
	30%	28%	17%	27%
	CI 29-31%	CI 24-31%	CI 13-21%	CI 23-31%
More than 50	78	3	2	3
years	1%	<1%	1%	1%
	CI 1-1%	CI 0-1%	CI 0-1%	CI 0-1%
I don't know	12	0	0	1
	<1%	0%	0%	<1%
				CI 0-1%
Total	6,720	689	298	448
	100%	100%	100%	100%

4. Access to services

In the last 12 months have you seen an MS specialist nurse in relation to your MS?

			Northern	
	England	Scotland	Ireland	Wales
Yes	4,761	502	163	346
	71%	73%	54%	77%
	CI 70-72%	CI 70-76%	CI 49-60%	CI 73-81%
No, and I have not needed to	1,309	122	79	66
	19%	18%	26%	15%
	CI 18-20%	CI 15-21%	CI 21-31%	CI 12-18%
No, but I needed to	606	60	54	27
	9%	9%	18%	6%
	CI 8-10%	CI 7-11%	CI 14-22%	CI 4-8%
I'm not sure	58	3	4	10
	1%	<1%	1%	2%
	Cl 1-1%	CI 0-1%	CI 0-3%	CI 1-3%
TOTAL	6,735	687	300	449
	100%	100%	100%	100%

In the last 12 months have you seen a neurologist in relation to your MS?

			Northern	
	England	Scotland	Ireland	Wales
Yes	4,255	381	233	251
	64%	56%	78%	57%
	CI 63 - 65%	CI 53 - 60%	CI 74 - 83%	CI 52 - 62%
No, and I have not needed to	1,649	227	28	138
	25%	34%	9%	31%
	CI 25-26%	CI 34-37%	CI 6-13%	CI 27 - 36%
No, but I needed to	632	62	33	48
	10%	9%	11%	11%
	CI 9-10%	CI 7-11%	CI 7-15%	CI 8-14%
I'm not sure	90	7	4	4
	1%	1%	1%	1%
	CI 1-2%	CI 0-1%	CI 0-3%	CI 0-2%
TOTAL	6,626	677	298	441
	100%	99%	99%	100%

			Northern	
	England	Scotland	Ireland	Wales
Yes	2,332	210	89	178
	35%	31%	30%	40%
	CI 34 - 36%	CI 27 - 34%	CI 24 - 35%	Ci 35 - 44%
No, and I have not needed to	3,415	384	160	210
	51%	56%	53%	47%
	CI 50 -52%	CI 52 - 60%	CI 48 - 59%	CI 42 - 52%
No, but I needed to	833	85	47	52
	12%	12%	16%	12%
	Cl 12 - 13%	CI 10 -15%	CI 12 - 20%	CI 9 -15%
I'm not sure	99	5	4	8
	1%	1%	1%	2%
	CI 1 - 2%	CI 0 - 1%	CI 0 -3%	CI 1 - 3%
TOTAL	6,679	684	300	448
	99%	99%	100%	101%

In the last 12 months, have you seen a continence specialist?

In the last 12 months, have you received support for mood or emotional issues?

			Northern	
	England	Scotland	Ireland	Wales
Yes, from the NHS	1,020	132	44	70
	15%	19%	15%	16%
	CI 14-16%	CI 16 - 22%	CI 11 - 19%	Cl 12 - 19%
Yes, from a charity or voluntary	217	34	17	10
organisation	3%	5%	6%	2%
	CI 3 - 4%	CI 3 - 7%	CI 3 - 8%	CI 1 - 4%
Yes, from a private provider	219	21	10	9
	3%	3%	3%	2%
	CI 3 - 4%	CI 2 - 4%	CI 1 - 5%	CI 1 - 3%
Yes, from somewhere else	132	12	3	9
	2%	2%	1%	2%
	CI 2-2%	CI 1 - 3%	CI 0 -2%	CI 1 - 3%
Yes, but I needed more support	163	17	10	13
	2%	3%	3%	3%
	CI 2-3%	CI 3 - 4%	CI 1 - 6%	CI 1 - 5%
No, and I have not needed to	3,990	383	156	280
	60%	56%	52%	63%
	CI 59 -61%	CI 53 - 60%	CI 46 - 58%	CI 59 - 68%
No, but I needed to	1,111	113	67	67
	17%	17%	22%	15%
	CI 16 - 18%	CI 14 - 19%	CI 18 - 27%	Cl 12 - 18%
I'm not sure	153	13	5	9
	2%	2%	2%	2%
	CI 2-3%	Cl 1 - 3%	CI 0 -3%	Cl 1 - 3%
TOTAL	7,005	725	312	467
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In the last 12 months have you seen a physiotherapist in relation to your MS?

			Northern	
	England	Scotland	Ireland	Wales
Yes, from the NHS	1,943	192	95	130
	29%	28%	32%	29%
	CI 28 - 30%	Cl 25 - 31%	CI 26 - 37%	Cl 25 - 33%
Yes, from a charity or voluntary	417	48	24	17
organisation	6%	7%	7%	4%
	CI 6 - 7%	CI 5 - 9%	CI 4 - 10%	CI 2 - 6%
Yes, from a private provider	497	51	15	21
	7%	7%	5%	5%
	CI 7 - 8%	CI 5 - 9%	Cl 2 - 7%	Cl 3 - 7%
Yes, from somewhere else	73	9	2	7
	1%	1%	1%	1%
	CI 1 - 1%	CI 0 - 2%	CI 0 -1%	CI 0 - 3%
Yes, but I needed more support	203	21	6	16
	3%	3%	2%	3%
	CI 3 - 3%	CI 2 - 4%	CI 0 - 4%	CI 2 - 5%
No, and I have not needed to	2,825	303	110	199
	42%	44%	37%	45%
	CI 41 - 44%	CI 41 - 48%	CI 31 - 42%	CI 40 - 49%
No, but I needed to	1,047	103	62	74
	16%	15%	21%	17%
	CI 15 - 17%	Cl 12 - 18%	CI 16 - 25%	CI 13 - 20%
I'm not sure	82	8	2	9
	1%	1%	1%	2%
	CI 1 - 1%	CI 0 - 2%	CI 0 - 2%	CI 13 - 20%
TOTAL	7,087	735	318	473

			Northern	
	England	Scotland	Ireland	Wales
Yes, from the NHS	704	75	19	54
	11%	11%	6%	12%
	CI 10 - 11%	Cl 9 - 13%	CI 4 - 9%	Cl 9 - 15%
Yes, from a charity or voluntary	682	79	36	30
organisation	10%	12%	12%	7%
	CI 10 - 11%	Ci 9 - 14%	Cl 8 - 16%	CI 5 - 9%
Yes, from a private provider	416	43	8	16
	6%	6%	3%	4%
	CI 6 - 7%	CI 5 - 8%	Ci 1 - 4%	Cl 2 - 5%
Yes, I/my family paid for it	779	69	28	52
	12%	10%	9	12%
	Cl 11 - 13%	Cl 8 - 12%	CI 6 - 13%	Cl 9 - 15%
Yes, from somewhere else	219	31	10	13
	3%	4%	3%	3%
	CI 3 - 4%	CI 3 - 6%	CI 1 - 6%	Cl 1 - 5%
Yes, but I needed more support	173	16	12	9
	3%	2%	4%	2%
	CI 2 - 3%	CI 1 - 3%	CI 2 - 6%	Cl 1 - 3%
No, and I have not needed to	2,776	298	120	181
	42%	44%	40%	41%
	Ci 43 - 41%	CI 40 - 47%	CI 35 - 46%	CI 46 - 37%
No, but I needed to	1,444	136	74	103
	22%	20%	25%	23%
	Cl 23 - 21%	Cl 17 - 23%	CI 20 - 30%	Cl 19 - 27%
I'm not sure	170	6	8	14
	3%	1%	3%	3%
	CI 2 - 3%	CI 0 - 2%	Cl 1 - 5%	CI 2 - 5%
TOTAL	6,584	753	315	472

In the past 12 months have you received support to remain physically active?

5. Access to treatments and therapies

Proportion of people taking a disease modifying therapy who could benefit

At the time of the survey, there were no disease modifying treatments (DMTs) available on the NHS for people with primary progressive MS and very limited options for people with secondary progressive MS. Therefore, in this report when we refer to people that could 'potentially benefit from a DMT', this only includes respondents with relapsing forms of MS (both secondary progressive MS with relapses and relapsing remitting MS). We acknowledge that this will include some people that are not eligible for a DMT and exclude some people with progressive forms of MS that are.

	England	Scotland	Northern Ireland	Wales
Taking a DMT	2,269	246	180	134
	60%	61%	81%	52%
Not taking a DMT	1,538	155	44	126
	40%	39%	19%	48%
TOTAL	3,807	401	224	260
	100%	100%	100%	100%

Comparison of people seeing an MS nurse in the preceding 12 months and the proportion taking a DMT

		Taking a			
	Seen MS nurse	Yes	No	Total	
	Yes	2011	948	2959	ch.:
England	res	68%	32%	100%	Chi
LIIgiallu	No	246	575	821	Square p = <0.05
		30%	70%	100%	p = <0.05
	Yes	230	101	331	Chi
Scotland		70%	30%	100%	Chi Square
Scotianu	No	13	54	67	p = <0.05
	NO	19%	81%	100%	p (0.05
	Yes	114	16	130	Chi
Northern	163	88%	12%	100%	Chi Square
Ireland	No	62	28	90	p = <0.05
		69%	31%	100%	p (0.00
	Yes	127	85	212	Chi
Wales	163	60%	40%	100%	Chi Square
vvales	No	4	39	43	p = <0.05
	110	9%	91%	100%	P .0.00

Comparison of people seeing a neurologist in the preceding 12 months and the proportion taking a DMT $\,$

	_	Taking a DMT			
	Seen			_	
	neurologist	Yes	No	Total	
	Yes	1927	844	2771	
England		70%	30%	100%	Chi Square
Lingiana	No	305	630	935	p = <0.05
		33%	67%	100%	
	Yes	192	73	265	
Scotland	163	72%	28%	100%	Chi Square
Scotianu	No	50	78	128	p = <0.05
		39%	61%	100%	
	Yes	144	30	174	
Northern	163	83%	17%	100%	Chi Square
Ireland	No	33	14	47	p = <0.05
	NO	71%	29%	100%	
	Yes	126	56	182	
Wales	res	69%	31%	100%	Chi Square
vvales	No	7	65	72	p = <0.05
	NO	90%	10%	100%	

Comparison of people who have seen either a nurse OR a neurologist (or both) in the preceding 12 months and the proportion taking a DMT

		Taking	Taking a DMT		
	Seen neurologist OR	No.	Ne	Tatal	
	MS nurse	Yes	No	Total	
	Yes	2211	1230	3441	
England	105	64%	36%	100%	Chi Square
Lingianu	No	55	303	358	p = <0.05
	NO	15%	85%	100%	
	Yes	243	113	356	
Contland	163	68%	32%	100%	Chi Square
Scotland	No	3	42	45	p = <0.05
	NO	6%	94%	100%	
	Yes	161	32	193	
Northern	163	83%	17%	100%	Chi Square
Ireland	No	19	11	30	p = <0.05
	NO	63%	37%	100%	
	Yes	134	100	234	
Wales	fes	57%	43%	100%	Chi Square
vvales	No	0	25	25	p = <0.05
	NO	0%	100%	100%	

Have you received enough information from your healthcare professionals about drugs available to support the treatment of your MS?

			Northern	
	England	Scotland	Ireland	Wales
	2784	302	124	194
Yes, I have been provided with enough information	42%	44%	42%	43%
with enough information	CI 40 - 43%	CI 40 -48%	CI 36 - 48%	CI 39 - 48%
No, I have not been	1842	182	88	123
provided with enough	27%	27%	30%	28%
information	CI 26 - 29%	CI 23 - 30%	CI 25 - 35%	CI 23 - 32%
No, I have not sought this	2062	201	83	129
information from health	31%	29%	28%	29%
professionals	CI 30 - 32%	CI 26 - 33%	CI 23 - 33%	CI 25 - 33%
TOTAL	6688	685	295	446
	100%	100%	100%	100%

6. Care co-ordination

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

			Northern	
	England	Scotland	Ireland	Wales
GP	890	140	39	43
	14%	21%	13%	10%
	CI 13 - 14%	CI 18 - 24%	Ci 9 - 17%	CI 7 - 13%
MS Nurse	3495	344	119	284
	53%	51%	41%	64%
	CI 52 - 55%	CI 48 - 55%	CI 35 - 47%	CI 60 - 69%
Other specialist nurse	56	6	1	5
	1%	1%	<1%	1%
	CI 1 - 1%	CI 0 - 2%	CI 0 - 1%	CI 0 - 2%
Neurologist	1108	86	94	55
	17%	13%	32%	13%
	CI 16 - 18%	CI 10 - 15%	CI 27 - 38%	Cl 9 - 16%
Social worker	25	4	7	5*
	<1%	1%	3%	1%
	CI 0 - 1%	CI 0 - 1%	CI 1 - 4%	CI 0 - 2%
Physiotherapist/occupational	120	17	3	10
therapist	2%	2%	1%	2%
	CI 2 - 2%	CI 1 - 4%	CI 0 - 2%	CI 1 - 4%
Continence specialist	20	0	0	5*
	<1%	-	-	1%
	CI <1% - <1%	-	-	CI 0 - 1%
No one	476	45	15	19
	7%	7%	5%	4%
	CI 7 - 8%	CI 5 - 9%	Ci 3 - 8%	Ci 2 - 6%
l am not sure	350	28	13	20
	5%	4%	4%	5%
	CI 5 - 6%	CI 3 - 6%	CI 2 - 7%	CI 3 - 6%

To what extent do you feel the professionals who plan your care work well together?

			Northern	
	England	Scotland	Ireland	Wales
Completely	1136	136	69	84
	17%	20%	23%	19%
	CI 16 - 18%	CI 17 - 23%	CI 19 - 28%	CI 15 - 22%
To some extent	2490	269	87	154
	37%	39%	29%	34%
	CI 36 - 38%	CI 36 - 43%	CI 24 - 34%	CI 30 - 39%
Not at all	1058	89	54	62
	16%	13%	18%	14%
	CI 15 - 17%	CI 11 - 16%	CI 14 - 22%	CI 11 - 17%
I am not sure	781	72	52	67
	12%	11%	17%	15%
	Ci 11 - 12%	Cl 8 - 13%	CI 13 - 22%	CI 12 - 18%
Not applicable	1230	115	35	82
	18%	17%	12%	18%
	CI 17 - 19%	CI 14 - 20%	CI 8 - 15%	CI 15 - 22%
Tetel	6695	681	297	449
Total	100%	100%	99%	100%

Have you developed a plan for your healthcare with a health professional?

			Northern	
	England	Scotland	Ireland	Wales
Yes	1114	101	46	76
	17%	15%	15%	17%
	CI 16 - 18%	CI 12 - 17%	CI 11 - 19%	CI 13 - 20%
No, but I would like one	1536	157	89	109
	23%	23%	30%	24%
	Cl 22 - 24%	CI 20 - 26%	CI 25 - 35%	CI 20 - 28%
No, and I have not needed one	2583	262	84	160
	39%	38%	28%	36%
	CI 37 - 40%	CI 35 - 42%	CI 23 - 33%	CI 31 - 40%
I don't know what a care plan is	892	99	51	69
	13%	14%	17%	15%
	CI 12 - 14%	CI 12 - 17%	CI 13 - 21%	CI 12 - 19%
I am not sure	576	66	29	33
	8%	10%	10%	7%
	CI 8 - 9%	CI 7 - 12%	CI 6 - 13%	CI 5 - 10%
Total	6701	685	299	447
Total	100%	100%	100%	99%

7. Care and support

In the past 12 months have you received care and support to assist with daily living?

			Northern	
	England	Scotland	Ireland	Wales
Yes, I have received all the support I	2474	249	102	203
need	37%	36%	34%	45%
	CI 36 - 38%	CI 33 - 40%	CI 29 - 40%	CI 41 - 50%
Yes, I have received some support	795	83	49	53
but not enough	12%	12%	16%	12%
	CI 11-13%	CI 10 -15%	CI 12 - 21%	Cl 9 - 15%
No, I have not needed to	2911	298	120	160
	44%	44%	40%	36%
	CI 42-45%	CI 40 - 47%	CI 35 - 46%	CI 31 - 40%
No, but I needed to	376	41	20	20
	6%	6%	7%	5%
	CI 5 - 6%	CI 4 - 8%	CI 4 - 10%	CI 3 - 6%
l am not sure	120	12	6	11
	1%	2%	2%	2%
	CI 1 - 2%	CI 1 - 3%	CI 0 - 3%	CI 1 - 4%
Total	6676	683	297	447
Total	100%	100%	99%	100%

If you have not received all of the care and support you need in the past 12 months have you experienced any of the following?

			Northern	
	England	Scotland	Ireland	Wales
	620	65	42	38
I have felt lonely or isolated	66%	63%	64%	53%
	CI 63 - 69%	CI 54 - 73%	CI 52 - 75%	CI 41 - 64%
	207	13	20	9
I have been unable to work	22%	13%	30%	13%
	Cl 19 - 25%	CI 6 - 19%	CI 19 - 41%	CI 5 - 21%
I have had to reduce the	108	15	8	9
hours I work	11%	15%	13%	12%
	Cl 9 - 13%	Cl 8 - 21%	CI 5 - 21%	Cl 4 - 19%
	562	58	34	38
My health has deteriorated	60%	57%	52%	54%
	CI 56 - 63%	CI 47 - 66%	CI 39 - 64%	CI 42 - 65%
I have readed becaited	113	6	9	11
I have needed hospital treatment	12%	6%	14%	16%
treatment	CI 10 - 14%	CI 1 - 10%	CI 6 - 22%	CI 7 - 24%
I have not been able to leave	117	2	1	2
hospital because alternate	2%	2%	1%	3%
care was not available	CI 1 - 3%	CI 0 - 4%	CI 0 - 4%	CI 0 - 7%
Total respondents	944	103	65	71

	England	Scotland	Northern Ireland	Wales
90 +	712	61	27	58
	21%	18%	17%	22%
	CI 20 - 23%	CI 14 - 22%	CI 11 - 22%	CI 17 - 27%
50 -89	316	32	19	23
	9%	9%	12%	9%
	CI 8 - 10%	CI 6 - 12%	CI 7 - 17%	CI 5 - 9%
20 - 49	716	80	30	66
	21%	23%	18%	25%
	CI 20 - 23%	CI 19 - 28%	CI 12 - 24%	CI 20 - 30%
1-19	996	98	47	74
	30%	29%	29%	28%
	CI 28 - 31%	CI 24 - 33%	CI 22 - 37%	Cl 23 - 33%
None	251	23	9	16
	7%	7%	6%	6%
	CI 7 - 8%	CI 4 - 9%	CI 2 - 9%	Cl 3 - 9%
Not				
sure	377	50	28	26
	12%	14%	18%	10%
	Cl 10 - 12%	Cl 11 - 18%	CI 12 - 24%	CI 6 - 14%
Total	3368	344	160	263
Total	100%	100%	100%	100%

How many hours of care per week is provided by family and friends?

8. Income and employment

Which would you say comes closest to your feeling about your current household income?

			Northern	
	England	Scotland	Ireland	Wales
Living really comfortably	503	56	12	22
	7%	8%	4%	5%
	CI 7 - 8%	CI 6 - 10%	CI 2 - 6%	CI 3 - 7%
Living comfortably	2537	242	94	162
	38%	35%	32%	36%
	CI 37 - 39%	CI 32 - 39%	CI 26 - 37%	CI 32 - 41%
Neither comfortable nor	2367	268	114	177
struggling	35%	39%	38%	39%
	CI 34 - 36%	CI 35 - 43%	CI 33 - 44%	CI 35 - 44%
Struggling	757	76	51	58
	11%	11%	17%	13%
	CI 10 - 12%	Cl 9 - 13%	CI 13 - 21%	CI 10 - 16%
Really struggling	197	14	12	18
	3%	2%	4%	4%
	CI 3 - 3%	CI 1 - 3%	CI 2 - 6%	CI 2 - 6%
Prefer not to answer	368	31	14	14
	6%	5%	5%	3%
	CI 5 - 6%	CI 3 - 6%	CI 2 - 7%	CI 1 - 5%
Total	6729	687	297	451
Total	100%	100%	100%	100%

Feeling about current income and access to services and information

		England		Scot	land
		Struggling or really struggling on current income	Not struggling on current income	Struggling or really struggling on current income	Not struggling on current income
	Need met	719	3784	71	411
		86%	89%	86%	90%
MS specialist	Unmet need	120 14%	449 11%	12 14%	44
nurse		839	4233	83	10% 455
	Total	100%	100%	100%	100%
			re p< 0.05		re p> 0.05
		647	3394	52	313
	Need met	84%	88%	82%	87%
	l la se et se e el	125	464	11	47
Neurologist	Unmet need	16%	12%	18%	13%
	Total	772	3858	63	360
		100%	100%	100%	100%
		Chi squar	e p< 0.05	Chi square p> 0.05	
	Unmet need	428	2819	34	313
		59%	76%	51%	79%
Information		296	909	33	83
about		41%	24%	49%	21%
managing MS	Total	724	3728	67	396
		100%	100%	100%	100%
		Chi squar	-	Chi square p< 0.05	
	Need met	391	1802	39	162
		70%	75%	70%	72%
Specialist	Unmet need	170 30%	614 25%	17 30%	62 28%
continence support		561	25%	56	28%
support	Total	100%	100%	100%	100%
		Chi squar			re p> 0.05
		385	2127	34	218
	Need met	59%	70%	54%	70%
	11	271	921	29	91
Physiotherapy	Unmet need	41%	30%	46%	30%
	Total	656	3048	63	309
	Total	100%	100%	100%	100%
		Chi squar	e p< 0.05	Chi squar	re p< 0.05

		Northern Ireland		Wa	ales
		Struggling or really struggling on current income	Not struggling on current income	Struggling or really struggling on current income	Not struggling on current income
	Need met	34 66%	117 77%	60 88%	275 94%
		17	34	8	16
MS specialist	Unmet need	34%	23%	12%	6%
nurse		51	151	68	291
	Total	100%	100%	100%	100%
		Chi squar	e p> 0.05	Chi squar	e p> 0.05
	Need met	52	171	50	197
	Need met	84%	91%	78%	86%
	Unmet need	10	17	14	33
Neurologist	onnetheed	16%	9%	22%	14%
	Total	62	188	64	230
		100%	100%	100%	100%
			e p> 0.05	Chi square p> 0.05	
	Need met Unmet need Total	22	121	37	200
		44%	75%	65%	77%
Information		28	40	20	61
about managing MS		56%	25%	35%	23%
		50	161	57	261
		100%	100%	100%	
		18	e p< 0.05 67	31	re p> 0.05 142
	Need met	59%	69%	68%	80%
Specialist		12	30	14	35
continence	Unmet need	41%	31%	32%	20%
support		30	97	45	177
	Total	100%	100%	100%	100%
		Chi squar	e p> 0.05	Chi squar	e p> 0.05
	Need met	14	98	28	128
	need met	31%	76%	54%	66%
	Unmet need	32	34	23	64
Physiotherapy	Shinetheed	69%	25%	46%	34%
	Total	46	132	51	192
		100%	101%	100%	100%
		Chi squar	e p< 0.05	Chi squar	re p> 0.05

Comparison of respondents feeling about their current household income by receiving or not receiving benefits

		Struggling or really struggling on current income		Not struggling on current income		Total		
	Receiving benefits	733	18%	3371	82%	4104	100%	Chi square
England	Not receiving benefits	210	10%	1974	90%	2184	100%	p<0.05
	Receiving benefits	77	18%	358	82%	435	100%	Chi square
Scotland	Not receiving benefits	14	7%	202	93%	216	100%	p<0.05
	Receiving benefits	52	27%	141	73%	193	100%	Chi square
Northern Ireland	Not receiving benefits	8	9%	76	91%	84	100%	p<0.05
	Receiving benefits	61	19%	256	81%	317	100%	Chi square
Wales	Not receiving	1.4	1.70/	105	000/	110	100%	p>0.05
Wales	benefits	14	12%	105	88%	119	100%	

If you were on DLA and have been assessed for PIP has there been a change to the payment you now receive?

			Northern	
	England	Scotland	Ireland	Wales
	531	52	42	50
I receive more than before	28%	28%	28%	28%
	CI 26 - 30%	CI 21 - 34%	CI 21 -35%	CI 21 - 34%
	796	75	56	78
I receive the same as before	42%	40%	36%	43%
	CI 29 - 44%	CI 33 - 48%	CI 29 - 44%	CI 35 - 50%
	285	28	33	25
I receive less than before	15%	15%	22%	14%
	CI 13 - 16%	CI 10 - 20%	Cl 15 - 28%	Cl 9 - 18%
	46	1	2	4
I receive nothing now	2%	1%	2%	2%
	CI 2 - 3%	CI 0 - 2%	CI 0 - 3%	CI 1 - 7%
	259	30	19	24
I am not sure	13%	16%	12%	13%
	Cl 12 - 15%	CI 11 - 21%	Cl 7 - 18%	CI 8 - 18%
Tatal	1917	186	152	181
Total	100%	100%	100%	100%

Are you currently in paid employment?

Γ			Northern	
	England	Scotland	Ireland	Wales
	1036	136	62	67
Yes, employed full time	15%	20%	21%	15%
	Cl 15 - 16%	Cl 17 - 23%	CI 16 -25%	CI 12 - 18%
	940	90	68	55
Yes, employed part time	14%	13%	23%	12%
	CI 13 - 15%	Cl 11 - 16%	CI 18 - 28%	Cl 9 - 16%
	106	8	3	9
Yes, self-employed full time	2%	1%	1%	2%
	Cl 1 - 2%	CI 0 - 2%	CI 0 - 2%	CI 1 - 3%
Vec. colf employed part	234	33	6	11
Yes, self-employed part time	3%	5%	2%	2%
time	CI 3 - 4%	CI 3 - 6%	CI 0 - 3%	CI 1 - 4%
	147	12	3	4
No, looking for work	2%	2%	1%	1%
	CI 2 -3%	Cl 1 - 3%	CI 0 - 2%	CI 0 - 2%
	705	84	31	42
No, not looking for work	11%	12%	11%	9%
	Cl 10 -11%	Cl 10 - 15%	CI 7 - 14%	CI 7 - 12%
	2017	161	49	116
No, retired and receiving pension	30%	24%	17%	26%
pension	Cl 29 -31%	CI 20 - 27%	CI 12 - 21%	CI 22 - 30%
No, medically retired early	1887	204	85	156
due to ill health	28%	30%	29%	35%
due to in health	CI 27 - 29%	CI 26 - 33%	CI 23 - 34%	CI 31 - 39%
	60	1	10	2
No, student	1%	<1%	3%	<1%
	CI 1 - 1%	CI 0 - 1%	CI 1 - 5%	CI 0 - 1%
	362	37	20	16
I do volunteer work	5%	5%	7%	4%
	CI 5 - 6%	CI 4 - 7%	CI 4 - 10%	CI 2 - 5%
Total respondents	6703	686	296	445

]			Northern	
	England	Scotland	Ireland	Wales
Yes	527	45	40	38
	27%	21%	30%	30%
	CI 25 - 29%	CI 15 - 26%	Cl 23 - 38%	CI 22 - 29%
No, and I have not needed help	1138	148	63	69
	58%	67%	49%	55%
	CI 56 - 60%	CI 61 - 74%	CI 40 - 57%	CI 46 - 63%
No, but I needed support	260	23	27	17
	13%	10%	21%	14%
	CI 12 - 15%	CI 6 - 14%	CI 14 - 18%	CI 8 - 20%
l am not sure	33	4	0	1
	2%	2%	0%	1%
	Cl 1 - 2%	CI 0 - 3%	-	CI 0 - 3%
Total	1958	220	130	125
	100%	100%	100%	100%

In the past 12 months, have you received support to remain in employment?

We're the MS Society.

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

Together, we are strong enough to stop MS.

mssociety.org.uk



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