

A large, stylized orange graphic that resembles a thick, rounded arrow pointing to the right. It has a gradient from light orange at the top to dark orange at the bottom. The text is centered within this graphic.

Neurology Now - 2021
Impact of COVID-19 on
services – data tables

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August 2021

Let's stop MS together

Introduction

This report provides a selection of data tables to support the UK wide report Neurology Now.

We conducted a survey of 196 professionals across the UK between 17 - 31 August 2021 (2 responses received after the closing date have been included in data tables n=198). Within our study, we wanted to understand the impact of the pandemic on neurological services, professionals and the people they care for.

In this survey, a variety of professionals are represented. Respondents include; condition specific nurses (20%), neurology nurses (15%), physiotherapists (40%), and occupational therapists (5%). The remaining 20% of the sample are dieticians (3%), general neurologists (2%), Psychologists (2%), service managers (2%), speech and language therapists (2%). Out of the 39 condition specific nurses, 36 (96%) were MS specialists.

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.

Data tables

What is your role?

	Percent	Responses	CI
Condition specific nurse	20%	39	15-26%
Dietician	3%	5	1-6%
General neurologist	2%	4	1-5%
Neurology nurse	15%	30	11-21%
Occupational therapist	5%	10	3-9%
Physiotherapist	40%	79	33-47%
Psychologist	2%	3	0-5%
Service manager	2%	3	0-5%
Speech and language therapist	2%	4	1-5%
Other	10%	21	7-16%
Total	100%	198	

Are you a MS/ Parkinson's nurse?

	Percent	Responses	CI
MS Nurse	92%	36	79-98%
Parkinson's Nurse	8%	3	2-21%
Total	100%	39	

What kind of service do you work in?

	Percent	Responses	CI
Academic institution	1%	1	<.01-3%
Community provider	12%	24	8-17%
Health Board	1%	1	<.01-3%
Local Authority	1%	1	<.01-3%
Neuro Science	2%	3	0-5%
NHS Acute Trust (secondary care)	22%	43	17-28%
NHS Acute Trust (specialist neuroscience centre)	20%	39	15-26%
NHS Community Trust	23%	46	18-30%
Primary care	2.0%	4	1-5%
Private provider	10%	20	7-15%
Voluntary Sector	4%	8	2-8%
Other	4%	8	2-8%
Total	100%	198	

Where is your service based?

	Percent	Responses	CI
East Midlands	6%	11	3-10%
East of England	10%	19	6-15%
Greater London	13%	25	9-18%
North East	5%	9	2-9%
North West	8%	16	5-13%

Northern Ireland	4%	7	1-7%
Scotland	7%	13	4-11%
South East	18%	36	13-24%
South West	14%	28	10-20%
Wales	4%	7	1-7%
West Midlands	9%	18	6-14%
Yorkshire and the Humber	5%	9	2-9%
Total	100%	198	

Do any of the people who use your service pay for this privately?

	Percent	Responses	CI
No	80%	158	74-85%
Yes - Less than 10%	4%	7	1-7%
Yes - 10% – 25%	1%	2	0-4%
Yes - 25%-50%	1%	1	<.01-3%
Yes - about 50%	1%	1	<.01-3%
Yes - 50%-75%	2%	3	0-5%
Yes - More than 75%	12%	23	8-17%
Don't know / cannot estimate	2%	3	0-5%
Total	100%	198	

Please estimate, what proportion of your time is spent supporting people with progressive neurological conditions? For this question, we'd like to know about how much of your patient facing time is spent on progressive conditions such as MS and Parkinson's specifically, rather than other brain conditions such as stroke or traumatic brain injury.

	Percent	Responses	CI
Less than 10%	5%	9	2-9%
10%-25%	13%	26	9-17%
25%-50%	6%	12	3-10%
About 50%	11%	22	7-16%
50%-75%	15%	30	11-21%
More than 75%	48%	95	41-55%
I cannot estimate	2%	4	1-5%
Total	100%	198	

Please estimate, what proportion of your time is spent supporting people with Multiple Sclerosis?

	Percent	Responses	CI
None	5%	10	3-9%
Less than 10%	12%	24	8-17%
10%-25%	14%	27	9-19%
25%-50%	17%	33	12-23%
About 50%	5%	9	2-9%
50-75%	8%	15	5-12%

More than 75%	40%	79	33-47%
I cannot estimate	1%	1	<.01-3%
Total	100%	198	

How does your services current staffing levels compare to staffing levels before the pandemic?

	Percent	Responses	CI
We have fewer staff now	28%	56	22-35%
We have the same number of staff now	61%	121	54-68%
We have more staff now	10%	20	7-15%
Don't know	1%	1	<.01-3%
Total	100%	198	

How challenging do you find it to provide a good service for everyone on your caseload? N=198

	Extremely challenging	Very challenging	Fairly challenging	Slightly challenging	Not at all challenging	Don't know
Before Covid-19	15 (8%) CI=5-12%	48 (24%) CI=19-31%	74 (37%) CI=31-44%	37 (19%) CI=14-25%	18 (9%) CI=6-14%	6 (3%) CI=1-7%
Now	53 (27%) CI=21-33%	72 (36%) CI=30-43%	45 (23%) CI=17-29%	17 (9%) CI=5-13%	11 (6%) CI=3-10%	0 (0%) CI=0-1%

You said you find it challenging now, what is the impact of this on you and your colleagues? (Tick all that apply)

	Percent	Responses	CI
We have had to compromise the quality of care we would normally deliver	42%	79	33-47%
We are concerned that the safety of some of our patients may be compromised	32%	60	24-37%
We are unable to see everyone who needs to access our service in a timely way	73%	137	62-75%
We are concerned about staff recruitment and retention	33%	62	25-38%
We are concerned about staff morale	52%	98	43-56%
We are concerned about staff burnout	60%	113	50-64%
Other - Write In	21%	39	15-26%
No impact	3%	5	1-6%
Total	317%	593	

Do the people who use your service currently have access to the appropriate range of healthcare professionals, to meet their needs?

	Percent	Responses	CI
Yes completely	13%	26	9-19%
Yes to some extent	65%	129	58-71%
No	19%	38	14-25%
Don't know	3%	5	1-6%
Total	100%	198	

What are the gaps in the staff mix? (Tick all that apply)

	Percent	Responses	CI
Care worker	13%	22	7-16%
Condition specific nurse	27%	45	17-29%
District Nurse	5%	8	2-8%
General Neurologist	15%	25	9-18%
MS Coordinator	23%	38	14-25%
Neurology infusion nurse	5%	8	2-8%
Neurology Nurse	15%	25	9-18%
Neuro-rehabilitation consultant	33%	55	22-34%
Occupational therapist	32%	53	21-33%
Palliative care nurse	10%	16	5-13%
Pharmacist	9%	15	5-13%
Physiotherapist	29%	48	19-31%
Psychologist	46%	76	32-45%
Rehab/AHP support worker	20%	33	12-23%
Specialist MS Neurologist	22%	37	14-25%
Speech and language therapist	16%	26	10-19%
Don't know	1%	2	0-4%
Other - Write In	19%	31	11-21%
Total	337%	563	

On average, how long are waiting times for your service (i.e. for new or routine follow up appointments)? Please provide your best estimate

	Percent	Responses	CI
0-4 weeks	30%	59	24-37%
1-2 months	25%	50	20-32%
3-4 months	18%	36	13-24%
5-6 months	11%	21	7-16%
7-8 months	5%	10	3-9%
9-12 months	3%	6	1-7%
13-18 months	1%	2	0-4%
19-24 months	1%	1	<.01-3%
Don't know	3%	5	1-6%
Not applicable	4%	8	2-8%
Total	100%	198	

Have your service's average waiting times (for new or routine follow up appointments) increased since March 2020?

	Percent	Responses	CI
Yes	53%	104	46-60%
No, they've stayed the same	32%	63	26-39%
No, they've decreased	5%	10	3-9%
Don't know	6%	11	3-10%
Not applicable	5%	10	3-9%
Total	100%	198	

How much have your service's average waiting times (for new or routine follow up appointments) increased by since March 2020?
Please provide your best estimate

	Percent	Responses	CI
0-4 weeks	25%	26	18-34%
1-2 months	31%	32	23-40%
3-4 months	22%	23	15-31%
5-6 months	9%	9	4-16%
7-8 months	2%	2	0-7%
9-12 months	2%	2	0-7%
13-18 months	2%	2	0-7%
Don't know	8%	8	4-15%
Total	100%	104	

How long do you think it will take for you to return to similar waiting times as March 2020?

	Percent	Responses	CI
Within the next 3 months	5%	5	2-11%
In 3-6 months	11%	11	6-18%
In 6-12 months	31%	32	23-40%
Over a year to 5 years	22%	23	15-31%
More than 5 years	1%	1	<.001 -6%
Never	3%	3	1-9%
Don't know / can't say	28%	29	20-37%
Total	100%	104	

Do you think limitations to services due to COVID-19 could have any of the following impacts on people with progressive neurological conditions? (N= 198)

	Yes, for all	Yes for the majority	Yes, for the minority	No	Don't know
Long-lasting impact on physical health (for example through deconditioning)	34 (17%) CI=13-23%	108 (55%) CI=48-61%	48 (24%) CI=19-31%	1 (.5%) CI=<.01-3%	7 (4%) CI=2-7%
Short-term impact on physical health	43 (22%) CI=17-28%	102 (52%) CI=45-58%	47 (24%) CI=18-30%	2 (1%) CI=0-4%	4 (2%) CI=1-5%
Long-lasting impact on mental health and wellbeing (for example increased anxiety or low mood)	28 (14%) CI=10-20%	82 (41%) CI=35-48%	79 (40%) CI=33-47%	3 (2%) CI=0-5%	6 (3%) CI=1-7%
Short-term impact on mental health and wellbeing (for example increased anxiety or low mood)	41 (21%) CI=16-27%	107 (54%) CI=47-61%	45 (23%) CI=17-29%	2 (1%) CI=0-4%	3 (2%) CI=0-5%

In the next 5 years, what do you think the challenges will be for services for people with progressive neurological conditions? (Tick all that apply)

	Percent	Responses	CI
A reduction in hospital based neurology services	45%	89	38-52%
A reduction in community neurological services	50%	99	43-57%
Increased caseloads	88%	174	83-92%
Lack of funding for future service developments	77%	153	71-83%
Lack of succession planning	54%	107	47-61%
Limited capacity of services to deliver DMTs for people with progressive MS	46%	90	39-52%
Ongoing limitations to delivering face to face care	63%	124	56-69%
Ongoing unmet need for treatment and care	55%	109	48-62%
Reduced availability of therapy services	76%	151	70-82%
Seasonal delays in service provision (e.g. due to increased winter pressures)	46%	91	39-53%
Specialist staff leaving the workforce	64%	127	57-71%
Widening inequalities in service access	48%	95	41-55%
Other	8%	15	6-12%
Total	100%	198	

In the next 5 years, what do you think the opportunities will be for services for people with progressive neurological conditions? (Tick all that apply)

	Percent	Responses	CI
Access to virtual groups/training (e.g. online exercise groups)	84%	166	78-88%
Ability to see growing numbers of patients through virtual or telephone appointment	66%	131	59-72%
Greater partnership working with charities	44%	88	38-51%
Greater use of self-management technology	68%	134	61-74%
Increased/more effective use of virtual or telephone appointments	76%	151	70-82%
Improved triage processes	27%	54	22-34%
None	1%	2	0-4%
Other	9%	17	5-13%
Total	375%	743	

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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 **Let's stop MS together**