



National Neurology Patient Experience Survey 2018/19

Detailed Table of Results

Tourette syndrome

Produced by Quality Health

Survey Results

This report sets out the results from the National Neurology Patient Experience Survey 2018/19, ordered in exactly the same way as in the survey questionnaire provided to patients.

Reading the columns of figures

The results are shown firstly in absolute numbers, then as percentage responses for both Tourette syndrome and Nationally¹.

Conventions

The percentages are calculated after excluding those patients that did not answer that particular question. All percentages are rounded to the nearest whole number. When added together, the percentages for all answers to a particular question may not total 100% because of this rounding.

The number of patients that did not answer a particular question is shown as the 'missing' figure at the bottom of the actual number of responses.

On some questions there are figures which are italicised. These figures have been recalculated to exclude responses where the question was not applicable to the respondent's circumstances. For example, question 3 regarding quality of life where those not answering ("Missing") and those answering "Don't know" have been excluded.

¹Please note that the National Results presented in the data tables are based on an overall number of responses of 10,339. 6,834 of these were anonymous responses to the online survey and are therefore not attributed to any clinic. 3,505 of these were clinic level responses, either collected via paper-based surveys in clinics, or via unique online links advertised in clinics. These 3,505 responses have been used to report the individual clinic level results.

QUESTIONS ABOUT YOUR CONDITION

Q1. Who is filling in this survey?	Condition		National	
	Respondents	%	Respondents	%
I am filling it in as a neurology patient	51	50%	8,577	88%
A friend or family member is filling it in on my behalf	50	49%	1,049	11%
Other	2	2%	117	1%
Missing	5		596	

Q2. Please tell us which neurological condition(s) you have? (Primary conditions)	Condition		National	
	Respondents	%	Respondents	%
I am awaiting diagnosis	0	0%	640	6%
Acoustic neuroma	0	0%	32	0%
Acquired brain injury	0	0%	105	1%
Ataxia	0	0%	185	2%
Autoimmune encephalitis	0	0%	21	0%
Brain tumour	0	0%	109	1%
Cavernoma	0	0%	90	1%
Cerebral palsy	0	0%	28	0%
Charcot-Marie-Tooth disease	0	0%	45	0%
Chiari malformation	0	0%	40	0%
Chronic inflammatory demyelinating polyneuropathy	0	0%	68	1%
Cluster headache	0	0%	62	1%
Dementia - other (inc frontotemporal / Lewy body / vascular)	0	0%	33	0%
Dystonia	0	0%	530	5%
Encephalitis	0	0%	41	0%
Epilepsy	0	0%	1,157	11%
Essential tremor	0	0%	78	1%
Functional neurological disorder	0	0%	386	4%
Guillain-Barre syndrome	0	0%	160	2%
Hemifacial spasm	0	0%	41	0%

QUESTIONS ABOUT YOUR CONDITION (CONTINUED)

Q2. Please tell us which neurological condition(s) you have? (Primary conditions - continued)	Condition		National	
	Respondents	%	Respondents	%
Huntington's disease	0	0%	40	0%
Hydrocephalus	0	0%	59	1%
Idiopathic intracranial hypertension	0	0%	264	3%
Migraine	0	0%	726	7%
Motor neurone disease	0	0%	137	1%
Multiple sclerosis	0	0%	1,195	12%
Multiple system atrophy	0	0%	83	1%
Muscular dystrophy	0	0%	26	0%
Myalgic encephalomyelitis/chronic fatigue syndrome	0	0%	319	3%
Myasthenia	0	0%	278	3%
Narcolepsy	0	0%	100	1%
Parkinson's disease	0	0%	847	8%
Peripheral neuropathy	0	0%	49	0%
Post-Polio syndrome	0	0%	28	0%
Progressive supranuclear palsy	0	0%	34	0%
RLS	0	0%	280	3%
Spina bifida	0	0%	22	0%
Spinal condition	0	0%	31	0%
Stroke	0	0%	130	1%
Tourette syndrome	108	100%	108	1%
Transverse myelitis	0	0%	162	2%
Traumatic brain injury	0	0%	43	0%
Traumatic spinal injury	0	0%	30	0%
Trigeminal neuralgia	0	0%	88	1%
Other neurological condition	0	0%	540	5%
Multiple primary conditions	0	0%	578	6%
No primary condition	0	0%	291	3%

QUESTIONS ABOUT YOUR CONDITION (CONTINUED)

Q3. To what extent does your neurological condition impact your quality of life?	Condition		National	
	Respondents	%	Respondents	%
* To a great extent	40	37%	4,663	46%
* To a moderate extent	47	44%	3,597	35%
* To a small extent	17	16%	1,606	16%
* Not at all	3	3%	299	3%
Don't know	1	1%	88	1%
Missing	0		86	

Q4. To what extent does your neurological condition affect your day to day activities?	Condition		National	
	Respondents	%	Respondents	%
* To a great extent	38	35%	4,299	42%
* To a moderate extent	46	43%	3,591	35%
* To a small extent	19	18%	1,725	17%
* Not at all	5	5%	547	5%
Don't know	0	0%	73	1%
Missing	0		104	

Q5. To what extent does your neurological condition cause you pain or discomfort?	Condition		National	
	Respondents	%	Respondents	%
* To a great extent	32	30%	3,245	32%
* To a moderate extent	45	42%	3,438	34%
* To a small extent	20	19%	2,190	22%
* Not at all	9	8%	1,255	12%
Don't know	1	1%	117	1%
Missing	1		94	

QUESTIONS ABOUT YOUR CONDITION (CONTINUED)

Q6. Apart from your neurological conditions, do you live with any other conditions?	Condition		National	
	Respondents	%	Respondents	%
No	32	30%	4,321	43%
Yes	75	70%	5,743	57%
Missing	1		275	

BEFORE DIAGNOSIS

Q7. How many times did you see a GP about the health problems caused by your condition before you were told you needed to see a neurologist?	Condition		National	
	Respondents	%	Respondents	%
None – I did not see my GP before going to see a neurological specialist (includes emergency admissions)	5	5%	1,355	14%
* I saw my GP once or twice	27	35%	2,978	41%
* I saw my GP three to four times	21	27%	1,471	20%
* I saw my GP five or more times	30	38%	2,829	39%
N/A - I did not need to see a neurologist	17	16%	488	5%
Don't know / can't remember	6	6%	807	8%
Missing	2		411	

Q8. How long after first seeing your GP was it before you saw a neurologist?	Condition		National	
	Respondents	%	Respondents	%
Not applicable / I did not need to see a neurologist	19	18%	706	7%
I did not see a GP before I saw a neurologist (this includes emergency admissions)	7	6%	1,144	11%
* Less than 3 months	13	18%	2,480	34%
* 3-6 months	21	28%	1,824	25%
* 7-12 months	10	14%	900	12%
* More than 12 months	30	41%	2,073	28%
Don't know / can't remember	8	7%	1,078	11%
Missing	0		134	

BEFORE DIAGNOSIS (CONTINUED)

Q9. How long did you wait after your first visit to a neurologist until you obtained a confirmed and accurate diagnosis?	Condition		National	
	Respondents	%	Respondents	%
Not applicable / I did not need to see a neurologist	17	16%	670	7%
Not applicable / I was diagnosed immediately	38	35%	2,441	24%
* <i>I have a diagnosis but this has not been confirmed</i>	6	13%	615	10%
* <i>Less than 3 months</i>	16	34%	2,323	38%
* <i>3-6 months</i>	7	15%	1,263	21%
* <i>7-12 months</i>	0	0%	607	10%
* <i>More than 12 months</i>	18	38%	1,313	21%
Don't know / can't remember	6	6%	842	8%
Missing	0		265	

FINDING OUT ABOUT YOUR CONDITION

Q10. When were you first told you had a neurological condition (when were you first diagnosed)?	Condition		National	
	Respondents	%	Respondents	%
* <i>Less than 1 year ago</i>	20	19%	1,445	15%
* <i>1-2 years ago</i>	22	21%	1,418	15%
* <i>3-5 years ago</i>	26	25%	1,868	20%
* <i>6-10 years ago</i>	18	17%	1,667	18%
* <i>More than 10 years ago</i>	17	17%	3,058	32%
I have not received a diagnosis	0	0%	459	5%
Don't know / can't remember	4	4%	228	2%
Missing	1		196	

Q11. Did you/your family understand the explanation given to you at your diagnosis / when you were first told about your condition?	Condition		National	
	Respondents	%	Respondents	%
* <i>Yes, I/we completely understood it</i>	38	36%	3,639	38%
* <i>Yes, I/we understood some of it</i>	48	45%	3,798	39%
* <i>No, I/we did not understand it</i>	9	8%	1,197	12%
* <i>I/we were not given an explanation</i>	11	10%	1,046	11%
Don't know / can't remember	1	1%	352	4%
Missing	1		307	

INFORMATION ABOUT YOUR CONDITION

Q12. When you were told you had a neurological condition, were you given written information about this?	Condition		National	
	Respondents	%	Respondents	%
Yes, I was given the hospital's own written information	20	19%	2,140	21%
Missing	88		8,199	
Yes, I was given written information from a specific charity	13	12%	690	7%
Missing	95		9,649	
Yes, I was given the hospital's own written information and written information from a specific charity	6	6%	427	4%
Missing	102		9,912	
I was not offered written information	49	45%	4,430	43%
Missing	59		5,909	
I did not need written information	3	3%	580	6%
Missing	105		9,759	
Don't know / can't remember	6	6%	1,081	10%
Missing	102		9,258	
Other	4	4%	546	5%
Missing	104		9,793	

Q13. How would you rate the quality of this information?	Condition		National	
	Respondents	%	Respondents	%
* <i>Excellent</i>	11	17%	1,191	23%
* <i>Good</i>	18	28%	2,187	42%
* <i>Fair</i>	17	26%	962	18%
* <i>Poor</i>	19	29%	917	17%
Don't know	2	2%	471	5%
N/A	39	37%	4,198	42%
Missing	2		413	

INFORMATION ABOUT YOUR CONDITION (CONTINUED)

Q14. What did the health professional who gave you your diagnosis say about finding further information?	Condition		National	
	Respondents	%	Respondents	%
* I was told to contact the hospital	4	4%	857	11%
* I was told to contact a specific charity	15	16%	896	11%
* I was told to look at a specific website on the internet	31	33%	1,229	15%
* I was told to look at the internet but no website was specified	9	10%	499	6%
* I was not told anything about finding further information	34	37%	4,455	56%
Don't know / can't remember	14	13%	1,870	19%
Missing	1		533	

Q15. If you used the internet, which site(s) proved the most useful?	Condition		National	
	Respondents	%	Respondents	%
Social Media (Facebook / Twitter)	31	29%	1,656	16%
Missing	77		8,683	
NHS Website	29	27%	2,677	26%
Missing	79		7,662	
Patient.co.uk	3	3%	563	5%
Missing	105		9,776	
Net Doctor	5	5%	271	3%
Missing	103		10,068	
Don't know / I didn't use the internet	11	10%	2,274	22%
Missing	97		8,065	
Particular Charity / Other	48	44%	3,334	32%
Missing	60		7,005	

TREATMENT AND CARE

Q16. How long after diagnosis was it before you started receiving treatment for your neurological condition?	Condition		National	
	Respondents	%	Respondents	%
* <i>I was treated immediately</i>	16	25%	3,380	46%
* <i>Within a month</i>	14	22%	1,235	17%
* <i>1-2 months</i>	5	8%	698	9%
* <i>3-4 months</i>	12	18%	645	9%
* <i>5-6 months</i>	3	5%	351	5%
* <i>7-12 months</i>	4	6%	331	5%
* <i>Over a year</i>	11	17%	711	10%
I have been offered treatment but declined it	2	2%	121	1%
I still haven't been treated (I am waiting for this to happen)	19	18%	802	8%
There is currently no treatment available for my condition	13	12%	1,163	12%
Don't know / can't remember	7	7%	533	5%
Missing	2		369	

Q17. Do you currently take prescribed medication to manage your neurological condition or prevent it returning / getting worse?	Condition		National	
	Respondents	%	Respondents	%
* <i>Yes, and I pay for this prescription</i>	19	18%	1,921	19%
* <i>Yes - but I don't pay for this prescription</i>	34	32%	5,419	54%
* <i>No - I do not take any prescribed medication</i>	53	50%	2,656	27%
Don't know / can't remember	1	1%	64	1%
Missing	1		279	

Q18. Do you currently take any non-prescribed medication, or substances, to help manage your condition?	Condition		National	
	Respondents	%	Respondents	%
No	88	82%	7,325	73%
Yes	19	18%	2,665	27%
Missing	1		349	

TREATMENT AND CARE (CONTINUED)

Q19. Do you see a specialist nurse for your neurological condition?	Condition		National	
	Respondents	%	Respondents	%
* Yes	17	17%	3,635	39%
* No, but I would have liked this	64	64%	3,542	38%
* No, but I do not want / need this	19	19%	2,236	24%
Don't know	4	4%	306	3%
Missing	4		620	

Q20. Have you seen an occupational therapist (or other professional) to help with assistive equipment?	Condition		National	
	Respondents	%	Respondents	%
* Yes	15	14%	2,928	30%
* No	91	86%	6,894	70%
Don't know / can't remember	1	1%	193	2%
Missing	1		324	

TREATMENT AND CARE (CONTINUED)

Q22. How was the equipment you were advised to get paid for?	Condition		National	
	Respondents	%	Respondents	%
Self-funded	6	40%	657	22%
Missing	9		2,271	
Grant from charity	2	13%	121	4%
Missing	13		2,807	
Fundraised	0	0%	17	1%
Missing	15		2,911	
NHS funded	5	33%	1,521	52%
Missing	10		1,407	
Local Authority funded	0	0%	834	28%
Missing	15		2,094	
I could not afford this equipment, so I don't have it	1	7%	33	1%
Missing	14		2,895	
Other	2	13%	183	6%
Missing	13		2,745	

TREATMENT AND CARE (CONTINUED)

Q23. Were you offered treatment and therapy by any of the following?	Condition		National	
	Respondents	%	Respondents	%
Physiotherapy	3	3%	3,423	33%
Missing	105		6,916	
Speech and Language Therapy	5	5%	1,308	13%
Missing	103		9,031	
Dietetics	0	0%	442	4%
Missing	108		9,897	
Occupational Therapy	7	6%	1,700	16%
Missing	101		8,639	
Palliative care	0	0%	103	1%
Missing	108		10,236	
Neuropsychology or neuropsychiatry	19	18%	868	8%
Missing	89		9,471	
Audiology (help with your hearing)	0	0%	302	3%
Missing	108		10,036	
Optics (help with your eyesight)	0	0%	601	6%
Missing	108		9,738	
Counselling	29	27%	1,145	11%
Missing	79		9,194	
None of the above	52	48%	4,579	44%
Missing	56		5,760	
Don't know / can't remember	6	6%	303	3%
Missing	102		10,036	

TREATMENT AND CARE (CONTINUED)

Q24. Are there any forms of treatment and therapy you would have liked but were not offered?	Condition		National	
	Respondents	%	Respondents	%
Physiotherapy	16	15%	1,365	13%
Missing	92		8,974	
Speech and Language Therapy	4	4%	363	4%
Missing	104		9,976	
Dietetics	0	0%	524	5%
Missing	108		9,815	
Occupational Therapy	15	14%	1,017	10%
Missing	93		9,322	
Palliative care	1	1%	96	1%
Missing	107		10,243	
Neuropsychology or neuropsychiatry	27	25%	1,086	11%
Missing	81		9,253	
Audiology (help with your hearing)	0	0%	277	3%
Missing	108		10,062	
Optics (help with your eyesight)	0	0%	563	5%
Missing	108		9,776	
Counselling	34	31%	2,298	22%
Missing	74		8,041	
None of the above	26	24%	3,707	36%
Missing	82		6,632	
Don't know / can't remember	5	5%	856	8%
Missing	103		9,483	

HOSPITAL CARE

Q25. How many times have you had a planned admission to hospital (i.e. a scheduled stay in hospital) as a result of your condition in the past two years?	Condition		National	
	Respondents	%	Respondents	%
* <i>Never</i>	99	93%	7,883	80%
* <i>1-2 times</i>	4	4%	1,412	14%
* <i>3-5 times</i>	2	2%	338	3%
* <i>6-9 times</i>	1	1%	72	1%
* <i>10 or more times</i>	0	0%	117	1%
Don't know / can't remember	1	1%	186	2%
Missing	1		331	

Q26. How many times have you had an emergency admission to hospital (i.e. an unscheduled stay in hospital) as a result of your neurological condition in the past two years?	Condition		National	
	Respondents	%	Respondents	%
* <i>Never</i>	86	81%	7,046	71%
* <i>1-2 times</i>	16	15%	2,052	21%
* <i>3-5 times</i>	3	3%	534	5%
* <i>6-9 times</i>	1	1%	123	1%
* <i>10 or more times</i>	0	0%	135	1%
Don't know / can't remember	1	1%	146	1%
Missing	1		303	

HOSPITAL CARE (CONTINUED)

Q27. When were you last seen by a specialist for your neurological condition?	Condition		National	
	Respondents	%	Respondents	%
* Last month	15	16%	1,964	22%
* Within last 1-3 months	18	19%	2,115	23%
* Within last 4-6 months	17	18%	1,743	19%
* Within last 7-12 months	12	13%	1,289	14%
* A year or more ago	33	35%	2,005	22%
Don't know / can't remember	0	0%	207	2%
I have never been seen in hospital for my condition	11	10%	703	7%
Missing	2		313	

When I think about specialist care for my neurological condition...

Q28a. ...I am seen often enough for my needs.	Condition		National	
	Respondents	%	Respondents	%
* Agree	34	33%	4,633	49%
* Neither agree nor disagree	14	13%	1,615	17%
* Disagree	56	54%	3,160	34%
Not applicable	3	3%	462	5%
Missing	1		469	

Q28b. ...I am satisfied with the care I receive.	Condition		National	
	Respondents	%	Respondents	%
* Agree	29	28%	4,763	50%
* Neither agree nor disagree	17	16%	1,999	21%
* Disagree	58	56%	2,673	28%
Not applicable	3	3%	401	4%
Missing	1		503	

HOSPITAL CARE (CONTINUED)

Q28c. ...Information about my specialist treatment and my condition is effectively passed on to the people that care for me (such as my GP, nurse, or family carer).	Condition		National	
	Respondents	%	Respondents	%
* <i>Agree</i>	29	29%	4,558	52%
* <i>Neither agree nor disagree</i>	23	23%	1,788	20%
* <i>Disagree</i>	49	49%	2,494	28%
Not applicable	5	5%	884	9%
Missing	2		615	

Q28d. ...I got the care I needed at home after my hospital visit.	Condition		National	
	Respondents	%	Respondents	%
* <i>Agree</i>	16	30%	1,895	36%
* <i>Neither agree nor disagree</i>	8	15%	1,239	24%
* <i>Disagree</i>	29	55%	2,120	40%
Not applicable	53	50%	4,270	45%
Missing	2		815	

SUPPORT FOR YOUR CONDITION

Q29. Have you been offered a care plan to help manage your neurological condition?	Condition		National	
	Respondents	%	Respondents	%
Yes, by my health care team	6	6%	751	7%
Missing	102		9,588	
Yes, by my social care team	3	3%	245	2%
Missing	105		10,094	
Yes, by my health care team and by my social care team	0	0%	88	1%
Missing	108		10,251	
No, but I would like one	53	49%	2,788	27%
Missing	55		7,551	
I don't need a care plan	22	20%	3,729	36%
Missing	86		6,610	
I don't know what a care plan is	13	12%	1,756	17%
Missing	95		8,583	
Don't know / can't remember	7	6%	524	5%
Missing	101		9,815	

Q30. To what extent do you think having a care plan helps improve your quality of life?	Condition		National	
	Respondents	%	Respondents	%
* To a great extent	14	32%	1,082	32%
* To a moderate extent	20	45%	1,241	37%
* To a small extent	8	18%	544	16%
* Not at all	2	5%	467	14%
Don't know	22	21%	2,195	23%
N/A	38	37%	4,053	42%
Missing	4		757	

MENTAL WELLBEING

Q31. Have you been asked about your mental wellbeing by a health or social care professional?	Condition		National	
	Respondents	%	Respondents	%
* Yes	62	59%	3,988	42%
* No	43	41%	5,593	58%
Don't know / can't remember	2	2%	449	4%
Missing	1		309	

Q32. Have you been referred or signposted to support for your mental wellbeing by a health professional?	Condition		National	
	Respondents	%	Respondents	%
* Yes	46	46%	2,403	26%
* No, but I would have liked this	39	39%	2,821	30%
* No, and I did not want/need this	16	16%	4,112	44%
Don't know / can't remember	5	5%	509	5%
Missing	2		494	

Q33. Where were you referred or signposted?	Condition		National	
	Respondents	%	Respondents	%
To a neuropsychologist or neuropsychiatrist	8	17%	616	26%
Missing	38		1,787	
To a counsellor or therapist	21	46%	1,452	60%
Missing	25		951	
To a buddying / befriending support group	3	7%	167	7%
Missing	43		2,236	
Not sure / can't remember	4	9%	87	4%
Missing	42		2,316	
Other	12	26%	300	12%
Missing	34		2,103	

MENTAL WELLBEING (CONTINUED)

Q34. Did this support help you?	Condition		National	
	Respondents	%	Respondents	%
* Yes - it helped me feel better / more positive	23	59%	1,249	62%
* No - it did not make me feel better / more positive	13	33%	481	24%
* It was not suitable for me	3	8%	270	14%
I chose not to access it	2	4%	172	7%
Don't know / can't remember	4	9%	164	7%
Missing	63		8,003	

Q35. To what extent do you feel your mental wellbeing needs are being met?	Condition		National	
	Respondents	%	Respondents	%
* To a great extent	13	13%	932	13%
* To a moderate extent	17	18%	1,766	25%
* To a small extent	23	24%	1,613	22%
* Not at all	44	45%	2,879	40%
Don't know	6	6%	616	6%
N/A	4	4%	2,081	21%
Missing	1		452	

SOCIAL CARE

Q36. Do you receive care that you don't pay for from a friend or family member?	Condition		National	
	Respondents	%	Respondents	%
Yes, and this person is over 18	52	50%	4,170	43%
Yes, and this person is under 18	5	5%	160	2%
No	48	46%	5,274	55%
Missing	3		735	

Q37. Has your local council assessed your care and support needs to see if you are eligible to receive care or support?	Condition		National	
	Respondents	%	Respondents	%
* Yes, and I was eligible	8	10%	887	13%
* Yes, but I was not eligible	1	1%	359	5%
* Yes, and I am waiting to hear the result	0	0%	90	1%
* No	71	89%	5,632	81%
Don't know / can't remember	4	4%	240	2%
N/A	20	19%	2,438	25%
Missing	4		693	

Q38a. Are you receiving any of the following sources of social care? Homecare (e.g help in your home)	Condition		National	
	Respondents	%	Respondents	%
* Yes, I pay for this	1	1%	425	5%
* Yes, someone else pays for this	1	1%	221	2%
* This is part funded	1	1%	165	2%
* No	95	97%	8,309	91%
Don't know	3	3%	62	1%
Missing	7		1,157	

SOCIAL CARE (CONTINUED)

Q38b. Are you receiving any of the following sources of social care? Residential Care (e.g. living in a care home)	Condition		National	
	Respondents	%	Respondents	%
* Yes, I pay for this	0	0%	25	0%
* Yes, someone else pays for this	0	0%	39	0%
* This is part funded	0	0%	20	0%
* No	99	100%	8,757	99%
Don't know	2	2%	39	0%
Missing	7		1,459	

Q38c. Are you receiving any of the following sources of social care? Day Services (e.g. attending day centre)	Condition		National	
	Respondents	%	Respondents	%
* Yes, I pay for this	0	0%	52	1%
* Yes, someone else pays for this	1	1%	76	1%
* This is part funded	0	0%	37	0%
* No	98	99%	8,656	98%
Don't know	2	2%	38	0%
Missing	7		1,480	

Q38d. Are you receiving any of the following sources of social care? Community Transport	Condition		National	
	Respondents	%	Respondents	%
* Yes, I pay for this	0	0%	79	1%
* Yes, someone else pays for this	0	0%	105	1%
* This is part funded	0	0%	59	1%
* No	99	100%	8,564	97%
Don't know	2	2%	71	1%
Missing	7		1,461	

SOCIAL CARE (CONTINUED)

Q38e. Are you receiving any of the following sources of social care? Home Adaptations	Condition		National	
	Respondents	%	Respondents	%
* Yes, I pay for this	0	0%	401	4%
* Yes, someone else pays for this	2	2%	672	7%
* This is part funded	1	1%	236	3%
* No	97	97%	7,656	85%
Don't know	2	2%	96	1%
Missing	6		1,278	

Q38f. Are you receiving any of the following sources of social care? Supported Living	Condition		National	
	Respondents	%	Respondents	%
* Yes, I pay for this	1	1%	60	1%
* Yes, someone else pays for this	1	1%	60	1%
* This is part funded	2	2%	75	1%
* No	94	96%	8,525	98%
Don't know	3	3%	129	1%
Missing	7		1,490	

Q39. To what extent do you feel your care and support needs are being met?	Condition		National	
	Respondents	%	Respondents	%
* To a great extent	21	23%	1,907	25%
* To a moderate extent	15	16%	2,024	26%
* To a small extent	27	30%	1,600	21%
* Not at all	28	31%	2,167	28%
Don't know	15	14%	1,599	17%
Missing	2		1,042	

SOCIAL CARE (CONTINUED)

Q40. Has the main person who looks after you had a carers' assessment?	Condition		National	
	Respondents	%	Respondents	%
* Yes	10	15%	653	15%
* No	55	85%	3,810	85%
I do not know	1	1%	292	3%
I do not have a carer	21	20%	2,293	24%
N/A	18	17%	2,407	25%
Missing	3		884	

Q41. After having a carers' assessment, has the main person who looks after you gone on to receive some form of additional financial support to help care for you?	Condition		National	
	Respondents	%	Respondents	%
* Yes	3	30%	312	48%
* No	7	70%	338	52%
Don't know / can't remember	0	0%	57	8%
Missing	98		9,631	

WELFARE

Q42. Are you currently in education, employment or training?	Condition		National	
	Respondents	%	Respondents	%
Yes, I am in education	57	53%	582	6%
Missing	51		9,757	
Yes, I am in employment	28	26%	3,518	34%
Missing	80		6,821	
Yes, I am in training	0	0%	49	0%
Missing	108		10,290	
No, I am not in education, employment or training	20	19%	5,504	53%
Missing	88		4,835	
Don't know / prefer not to say	2	2%	219	2%
Missing	106		10,120	

Thinking about your employment status, how much do you agree or disagree with the following statements?

Q43a. I have been able to continue work as normal since my neurological condition was diagnosed.	Condition		National	
	Respondents	%	Respondents	%
* Agree	18	31%	1,804	28%
* Neither agree nor disagree	10	17%	737	11%
* Disagree	30	52%	4,002	61%
Not applicable	42	42%	2,624	29%
Missing	8		1,172	

Q43b. My employer has supported me through my diagnosis and treatment.	Condition		National	
	Respondents	%	Respondents	%
* Agree	15	41%	2,240	48%
* Neither agree nor disagree	13	35%	955	21%
* Disagree	9	24%	1,443	31%
Not applicable	63	63%	4,440	49%
Missing	8		1,261	

WELFARE (CONTINUED)

Q43c. I have chosen to leave work due to the diagnosis of my neurological condition.	Condition		National	
	Respondents	%	Respondents	%
* <i>Agree</i>	10	37%	1,552	36%
* <i>Neither agree nor disagree</i>	5	19%	504	12%
* <i>Disagree</i>	12	44%	2,249	52%
Not applicable	73	73%	4,721	52%
Missing	8		1,313	

Q43d. I have missed out on opportunities to develop my career due to my neurological condition.	Condition		National	
	Respondents	%	Respondents	%
* <i>Agree</i>	39	76%	3,749	68%
* <i>Neither agree nor disagree</i>	6	12%	675	12%
* <i>Disagree</i>	6	12%	1,088	20%
Not applicable	49	49%	3,539	39%
Missing	8		1,288	

Q43e. I have chosen to take early retirement due to the effects of my neurological condition.	Condition		National	
	Respondents	%	Respondents	%
* <i>Agree</i>	1	8%	1,447	38%
* <i>Neither agree nor disagree</i>	2	17%	396	10%
* <i>Disagree</i>	9	75%	1,952	51%
Not applicable	88	88%	5,296	58%
Missing	8		1,248	

WELFARE (CONTINUED)

Q43f. I can no longer carry out my job due to the effects of my neurological condition.	Condition		National	
	Respondents	%	Respondents	%
* Agree	14	35%	3,015	54%
* Neither agree nor disagree	9	23%	877	16%
* Disagree	17	43%	1,693	30%
Not applicable	61	60%	3,519	39%
Missing	7		1,235	

Q43g. I have been discriminated against due to my neurological condition.	Condition		National	
	Respondents	%	Respondents	%
* Agree	28	55%	1,799	35%
* Neither agree nor disagree	10	20%	884	17%
* Disagree	13	25%	2,507	48%
Not applicable	49	49%	3,809	42%
Missing	8		1,340	

Q43h. My contract of employment has been terminated due to my neurological condition.	Condition		National	
	Respondents	%	Respondents	%
* Agree	7	29%	1,191	29%
* Neither agree nor disagree	3	13%	389	9%
* Disagree	14	58%	2,586	62%
Not applicable	76	76%	4,846	54%
Missing	8		1,327	

WELFARE (CONTINUED)

Q44. Are you, or a family / friend who cares for you, in receipt of any of the following benefits?	Condition		National	
	Respondents	%	Respondents	%
I am in receipt of Disability Living Allowance (DLA)	18	17%	1,118	11%
Missing	90		9,221	
I am in receipt of Personal Independence Payments (PIP)	24	22%	2,525	24%
Missing	84		7,814	
I am in receipt of Employment and Support Allowance (ESA)	12	11%	1,569	15%
Missing	96		8,770	
I have a Blue Badge	8	7%	2,844	28%
Missing	100		7,495	
I am in receipt of Job Seekers' Allowance (JSA)	1	1%	56	1%
Missing	107		10,283	
I am in receipt of Universal Credit	8	7%	283	3%
Missing	100		10,056	
I / we have Council Tax reduction	10	9%	1,422	14%
Missing	98		8,917	
My carer is in receipt of Carers' Allowance	9	8%	673	7%
Missing	99		9,666	
I am in receipt of Attendance Allowance	0	0%	391	4%
Missing	108		9,948	
I / we do not receive any of these benefits	46	43%	3,940	38%
Missing	62		6,398	
Don't know / prefer not to say	1	1%	256	2%
Missing	107		10,083	
Other	3	3%	322	3%
Missing	105		10,017	

WELFARE (CONTINUED)

Q45. Do you feel your financial needs are being met?	Condition		National	
	Respondents	%	Respondents	%
* Yes	46	55%	4,114	57%
* No	37	45%	3,155	43%
Don't know / prefer not to say	21	20%	2,317	24%
Missing	4		753	

HEALTH AND SOCIAL CARE IN GENERAL

Q46a. Do you feel fully involved in making choices about your health and social care? Social Care	Condition		National	
	Respondents	%	Respondents	%
* Yes, definitely	17	26%	1,907	35%
* Yes, to some extent	12	18%	1,214	22%
* Not really	19	29%	1,169	22%
* Not at all	17	26%	1,137	21%
Don't know / N/A	38	37%	3,957	42%
Missing	5		955	

Q46b. Do you feel fully involved in making choices about your health and social care? Health Care	Condition		National	
	Respondents	%	Respondents	%
* Yes, definitely	23	29%	3,033	39%
* Yes, to some extent	26	33%	2,434	31%
* Not really	14	18%	1,395	18%
* Not at all	17	21%	925	12%
Don't know / N/A	24	23%	1,717	18%
Missing	4		835	

Q47a. Have you experienced any problems or delays in accessing health care services or social care services to help manage your condition? Social Care	Condition		National	
	Respondents	%	Respondents	%
* Yes	35	63%	1,699	43%
* No	21	38%	2,231	57%
Don't know / N/A	44	44%	5,385	58%
Missing	8		1,024	

HEALTH AND SOCIAL CARE IN GENERAL (CONTINUED)

Q47b. Have you experienced any problems or delays in accessing health care services or social care services to help manage your condition? Health Care	Condition		National	
	Respondents	%	Respondents	%
* Yes	66	79%	3,827	55%
* No	18	21%	3,183	45%
Don't know / N/A	21	20%	2,618	27%
Missing	3		711	

Q48a. Overall, how do you rate the care and treatment you have received for your condition? Social Care	Condition		National	
	Respondents	%	Respondents	%
* Very good	8	12%	797	19%
* Good	10	15%	877	21%
* Fair	12	18%	966	23%
* Poor	35	54%	1,513	36%
Don't know / N/A	39	38%	5,124	55%
Missing	4		1,062	

Q48b. Overall, how do you rate the care and treatment you have received for your condition? Health Care	Condition		National	
	Respondents	%	Respondents	%
* Very good	13	14%	2,419	29%
* Good	15	16%	2,439	29%
* Fair	21	22%	1,919	23%
* Poor	45	48%	1,694	20%
Don't know / N/A	11	10%	1,228	13%
Missing	3		640	

HEALTH AND SOCIAL CARE IN GENERAL (CONTINUED)

Q49a. Please indicate how much you agree with the following statements: Overall, the health care I have received meets my needs.	Condition		National	
	Respondents	%	Respondents	%
* <i>Agree</i>	25	25%	4,447	49%
* <i>Neither agree nor disagree</i>	27	27%	2,334	26%
* <i>Disagree</i>	49	49%	2,358	26%
Not applicable	6	6%	724	7%
Missing	1		476	

Q49b. Please indicate how much you agree with the following statements: Overall, the social care I have received meets my needs.	Condition		National	
	Respondents	%	Respondents	%
* <i>Agree</i>	16	21%	1,441	30%
* <i>Neither agree nor disagree</i>	18	24%	1,515	32%
* <i>Disagree</i>	41	55%	1,839	38%
Not applicable	30	29%	4,719	50%
Missing	3		825	

ABOUT YOU

Q53. Age Band (derived from "What is your year of birth?")	Condition		National	
	Respondents	%	Respondents	%
Under 18	46	45%	227	2%
18-24 years old	19	19%	438	5%
25-34 years old	15	15%	1,010	11%
35-44 years old	11	11%	1,412	15%
45-54 years old	9	9%	2,026	21%
55-64 years old	1	1%	2,015	21%
65-74 years old	1	1%	1,674	18%
75 years or older	0	0%	642	7%
Missing	6		895	

Q54. What gender are you?	Condition		National	
	Respondents	%	Respondents	%
Male	61	59%	3,106	32%
Female	41	40%	6,631	68%
Prefer not to say	1	1%	70	1%
I prefer to use my own term (please specify)	0	0%	15	0%
Missing	5		517	

ABOUT YOU (CONTINUED)

Q55. To which of these ethnic groups do you belong?	Condition		National	
	Respondents	%	Respondents	%
English / Welsh / Scottish / Northern Irish / British	95	92%	8,954	92%
Irish	1	1%	101	1%
Gypsy or Irish traveller	0	0%	6	0%
Any other white background	1	1%	232	2%
White and black Caribbean	1	1%	52	1%
White and black African	0	0%	11	0%
White and Asian	2	2%	40	0%
Any other mixed background	2	2%	34	0%
Indian	1	1%	84	1%
Bangladeshi	0	0%	10	0%
Chinese	0	0%	9	0%
Any other Asian background	0	0%	57	1%
Caribbean	0	0%	51	1%
African	0	0%	28	0%
Any other Black background	0	0%	7	0%
Arab	0	0%	3	0%
Any other ethnic group	0	0%	45	0%
Missing	5		615	