

Q1 What age are you?

Answered: 504 Skipped: 0

ANSWER CHOICES	RESPONSES	
18	4.56%	23
19	3.77%	19
20	4.56%	23
21	6.15%	31
22	3.97%	20
23	6.55%	33
24	5.95%	30
25	6.75%	34
26	6.35%	32
27	4.37%	22
28	6.75%	34
29	5.56%	28
30	3.97%	20
31	4.76%	24
32	4.96%	25
33	5.75%	29
34	4.96%	25
35	10.32%	52
TOTAL		504

Q2 What is your gender?

Answered: 504 Skipped: 0

ANSWER CHOICES	RESPONSES	
Female	85.91%	433
Male	12.70%	64
Prefer not to say	0.40%	2
Other	0.99%	5
TOTAL		504

Q3 In what country do you live?

Answered: 504 Skipped: 0

ANSWER CHOICES	RESPONSES	
Albania	0.00%	0
Andorra	0.00%	0
Armenia	0.00%	0
Austria	0.40%	2
Azerbaijan	0.00%	0
Belarus	0.00%	0
Belgium	2.18%	11
Bosnia and Herzegovina	0.00%	0
Bulgaria	0.00%	0
Croatia	0.20%	1
Cyprus	0.00%	0
Czech Republic	0.00%	0
Denmark	3.37%	17
Estonia	0.00%	0
Finland	0.40%	2
France	0.40%	2
Georgia	0.00%	0
Germany	1.39%	7
Greece	0.00%	0
Hungary	0.00%	0
Iceland	0.20%	1
Ireland	0.20%	1
Italy	0.79%	4
Kazakhstan	0.00%	0
Kosovo	0.00%	0
Latvia	0.00%	0
Liechtenstein	0.00%	0
Lithuania	0.00%	0
Luxembourg	0.00%	0
Macedonia (FYROM)	0.00%	0

Survey of Young Europeans with Neurological Conditions

Malta	0.00%	0
Moldova	0.00%	0
Monaco	0.00%	0
Montenegro	0.00%	0
Netherlands	4.17%	21
Norway	67.86%	342
Poland	0.00%	0
Portugal	0.60%	3
Romania	0.00%	0
Russia	0.00%	0
San Marino	0.00%	0
Serbia	0.00%	0
Slovakia	0.00%	0
Slovenia	0.00%	0
Spain	0.79%	4
Sweden	1.19%	6
Switzerland	0.40%	2
Turkey	0.00%	0
Ukraine	0.00%	0
United Kingdom (UK)	15.48%	78
Vatican City (Holy See)	0.00%	0
TOTAL		504

Q4 Are you currently:

Answered: 496 Skipped: 8

ANSWER CHOICES	RESPONSES	
Studying full-time	6.05%	30
Studying part-time	10.08%	50
Employed full-time	8.47%	42
Employed part-time	9.68%	48
Unemployed and seeking work	2.22%	11
Unemployed and not seeking work	62.90%	312
Self-employed	2.22%	11
Total Respondents: 496		

Q5 What level of education have you achieved so far?

Answered: 497 Skipped: 7

ANSWER CHOICES	RESPONSES	
Completed high school/second level	36.82%	183
Certificate	6.04%	30
Diploma	8.65%	43
Bachelor's Degree	21.53%	107
Master's Degree	8.05%	40
PhD	0.40%	2
Other (please specify)	18.51%	92
TOTAL		497

Q6 What neurological disorder(s) are you affected by? (Tick all that apply)

Answered: 504 Skipped: 0

ANSWER CHOICES	RESPONSES	
Myalgic Encephalomyelitis (ME)	100.00%	504
Chronic pain	22.82%	115
Migraine	17.26%	87
Other (please specify)	7.54%	38
Restless Legs Syndrome (RLS)	6.35%	32
ADHD	4.56%	23
Multiple Sclerosis (MS)	1.19%	6
Acquired Brain Injury (ABI)	0.60%	3
Brain Tumour	0.60%	3
Dystonia	0.60%	3
Tourette Syndrome	0.40%	2
Myasthenia Gravis	0.20%	1
Spina Bifida and Hydrocephalus	0.20%	1
Ataxia	0.00%	0
Dementia	0.00%	0
Epilepsy	0.00%	0
Huntington's disease	0.00%	0
Motor Neurone Disease (MND)	0.00%	0
Parkinson's disease	0.00%	0
Stroke	0.00%	0
Total Respondents: 504		

Q7 Do you take prescribed medication for the above?

Answered: 501 Skipped: 3

ANSWER CHOICES	RESPONSES	
Yes	40.92%	205
No	52.10%	261
Previously, but not now	6.99%	35
TOTAL		501

Q8 Are you currently under treatment of a specialist/neurologist?

Answered: 500 Skipped: 4

ANSWER CHOICES	RESPONSES	
Yes	19.20%	96
No	64.20%	321
Previously, but not now	16.60%	83
TOTAL		500

Q9 Are other members of your family affected by a neurological disorder?

Answered: 502 Skipped: 2

ANSWER CHOICES	RESPONSES	
Yes	46.41%	233
No	39.64%	199
Unsure	13.94%	70
TOTAL		502

Q10 How well do you feel your family understand your condition?

Answered: 484 Skipped: 20

ANSWER CHOICES	AVERAGE NUMBER	TOTAL NUMBER	RESPONSES
	57	27,670	484
Total Respondents: 484			

Q11 How well do you feel your friends understand your condition?

Answered: 481 Skipped: 23

ANSWER CHOICES	AVERAGE NUMBER	TOTAL NUMBER	RESPONSES
	38	18,393	481
Total Respondents: 481			

Q12 How comfortable would you feel discussing your brain disorder with a new friend?

Answered: 479 Skipped: 25

ANSWER CHOICES	AVERAGE NUMBER	TOTAL NUMBER	RESPONSES
	44	21,103	479
Total Respondents: 479			

Q13 How comfortable would you feel discussing your brain disorder with an employer?

Answered: 477 Skipped: 27

ANSWER CHOICES	AVERAGE NUMBER	TOTAL NUMBER	RESPONSES
	28	13,501	477
Total Respondents: 477			

Q14 Do you feel public understanding of your condition is:

Answered: 478 Skipped: 26

ANSWER CHOICES	AVERAGE NUMBER	TOTAL NUMBER	RESPONSES
	14	6,505	478
Total Respondents: 478			

Q15 Do you feel public understanding of brain disorders generally is:

Answered: 478 Skipped: 26

ANSWER CHOICES	AVERAGE NUMBER	TOTAL NUMBER	RESPONSES
	26	12,648	478
Total Respondents: 478			

Q16 Are there any digital tools which help you with the management of your neurological disorder?

Answered: 487 Skipped: 17

ANSWER CHOICES	RESPONSES	
Yes	16.22%	79
No	77.00%	375
I tried something but stopped using it	6.78%	33
TOTAL		487

Q17 If 'Yes', what are they called?

Answered: 68 Skipped: 436

Q18 If you previously tried a digital tool but stopped using it, why was that?

Answered: 79 Skipped: 425

ANSWER CHOICES	RESPONSES	
Too difficult to use	31.65%	25
It was boring	6.33%	5
It seemed ineffective	40.51%	32
I'm worried about how my personal health data might be used	13.92%	11
Other (please specify)	22.78%	18
Total Respondents: 79		

Q19 Have you ever taken part in any awareness-raising activities relating to brain disorder/your own condition?

Answered: 483 Skipped: 21

ANSWER CHOICES	RESPONSES	
Yes	39.96%	193
No	60.04%	290
TOTAL		483

Q20 If 'No', is this something you would be interested in?

Answered: 287 Skipped: 217

ANSWER CHOICES	RESPONSES	
Yes	63.41%	182
No	36.59%	105
TOTAL		287

Q21 Are you a member of a patient organisation?

Answered: 480 Skipped: 24

ANSWER CHOICES	RESPONSES	
Yes	48.75%	234
No	46.25%	222
In the past, but not now	5.00%	24
TOTAL		480

Q22 If 'No', would you be interested in finding out more about one?

Answered: 196 Skipped: 308

ANSWER CHOICES	RESPONSES	
Yes	63.78%	125
No	36.22%	71
TOTAL		196

Q23 Patient organisations need to know about the issues that affect you most as a young person with a neurological condition. Please arrange the issues below so that the most serious issue is at the top (1) and the least serious is at the bottom (8).

Answered: 451 Skipped: 53

	1	2	3	4	5	6	7	8	TOTAL	SCORE
Access to employment	5.54% 25	7.10% 32	8.20% 37	7.76% 35	15.30% 69	19.96% 90	18.85% 85	17.29% 78	451	3.58
Access to education	4.66% 21	6.43% 29	7.54% 34	11.53% 52	15.74% 71	17.07% 77	23.28% 105	13.75% 62	451	3.60
Depression / anxiety	4.21% 19	6.43% 29	13.08% 59	13.97% 63	16.63% 75	12.86% 58	9.53% 43	23.28% 105	451	3.75
Relationships and sexual health	3.77% 17	8.65% 39	8.43% 38	18.85% 85	13.97% 63	14.19% 64	16.41% 74	15.74% 71	451	3.82
Cost of medication/treatment	4.21% 19	9.98% 45	13.08% 59	12.42% 56	11.75% 53	17.07% 77	12.86% 58	18.63% 84	451	3.87
Stigma surrounding brain disease	13.08% 59	21.06% 95	18.85% 85	13.75% 62	12.20% 55	8.20% 37	7.98% 36	4.88% 22	451	5.28
Isolation	19.73% 89	20.40% 92	22.39% 101	13.97% 63	9.31% 42	6.21% 28	5.10% 23	2.88% 13	451	5.74
Access to medication/treatment	44.79% 202	19.96% 90	8.43% 38	7.76% 35	5.10% 23	4.43% 20	5.99% 27	3.55% 16	451	6.37