

Q1 What age are you?

Answered: 63 Skipped: 0

ANSWER CHOICES	RESPONSES	
18	3.17%	2
19	1.59%	1
20	0.00%	0
21	1.59%	1
22	3.17%	2
23	3.17%	2
24	1.59%	1
25	4.76%	3
26	4.76%	3
27	1.59%	1
28	1.59%	1
29	3.17%	2
30	6.35%	4
31	9.52%	6
32	4.76%	3
33	12.70%	8
34	12.70%	8
35	23.81%	15
TOTAL		63

Q2 What is your gender?

Answered: 63 Skipped: 0

ANSWER CHOICES	RESPONSES	
Female	73.02%	46
Male	26.98%	17
Prefer not to say	0.00%	0
Other	0.00%	0
TOTAL		63

Q3 In what country do you live?

Answered: 63 Skipped: 0

ANSWER CHOICES	RESPONSES	
Albania	0.00%	0
Andorra	0.00%	0
Armenia	1.59%	1
Austria	0.00%	0
Azerbaijan	0.00%	0
Belarus	1.59%	1
Belgium	1.59%	1
Bosnia and Herzegovina	0.00%	0
Bulgaria	0.00%	0
Croatia	1.59%	1
Cyprus	0.00%	0
Czech Republic	0.00%	0
Denmark	0.00%	0
Estonia	0.00%	0
Finland	9.52%	6
France	0.00%	0
Georgia	0.00%	0
Germany	1.59%	1
Greece	0.00%	0
Hungary	0.00%	0
Iceland	0.00%	0
Ireland	1.59%	1
Italy	7.94%	5
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	1.59%	1
Moldova	0.00%	0
Monaco	0.00%	0
Montenegro	0.00%	0
Netherlands	3.17%	2
Norway	3.17%	2
Poland	47.62%	30
Portugal	0.00%	0
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	4.76%	3
Sweden	1.59%	1
Switzerland	0.00%	0
Turkey	0.00%	0
Ukraine	0.00%	0
United Kingdom (UK)	11.11%	7
Vatican City (Holy See)	0.00%	0
TOTAL		63

Q4 Are you currently:

Answered: 62 Skipped: 1

ANSWER CHOICES	RESPONSES	
Studying full-time	8.06%	5
Studying part-time	11.29%	7
Employed full-time	38.71%	24
Employed part-time	14.52%	9
Unemployed and seeking work	12.90%	8
Unemployed and not seeking work	19.35%	12
Self-employed	6.45%	4
Total Respondents: 62		

Q5 What level of education have you achieved so far?

Answered: 62 Skipped: 1

ANSWER CHOICES	RESPONSES	
Completed high school/second level	30.65%	19
Certificate	6.45%	4
Diploma	11.29%	7
Bachelor's Degree	20.97%	13
Master's Degree	22.58%	14
PhD	0.00%	0
Other (please specify)	8.06%	5
TOTAL		62

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

Answered: 63 Skipped: 0

ANSWER CHOICES	RESPONSES	
Dystonia	100.00%	63
Chronic pain	19.05%	12
Migraine	12.70%	8
Other (please specify)	12.70%	8
Restless Legs Syndrome (RLS)	9.52%	6
Epilepsy	7.94%	5
Ataxia	6.35%	4
Multiple Sclerosis (MS)	6.35%	4
Acquired Brain Injury (ABI)	4.76%	3
Myalgic Encephalomyelitis (ME)	4.76%	3
ADHD	1.59%	1
Motor Neurone Disease (MND)	1.59%	1
Parkinson's disease	1.59%	1
Stroke	1.59%	1
Brain Tumour	0.00%	0
Dementia	0.00%	0
Huntington's disease	0.00%	0
Myasthenia Gravis	0.00%	0
Spina Bifida and Hydrocephalus	0.00%	0
Tourette Syndrome	0.00%	0
Total Respondents: 63		

Q7 Do you take prescribed medication for the above?

Answered: 62 Skipped: 1

ANSWER CHOICES	RESPONSES	
Yes	67.74%	42
No	19.35%	12
Previously, but not now	12.90%	8
TOTAL		62

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

Answered: 62 Skipped: 1

ANSWER CHOICES	RESPONSES	
Yes	82.26%	51
No	8.06%	5
Previously, but not now	9.68%	6
TOTAL		62

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

Answered: 62 Skipped: 1

ANSWER CHOICES	RESPONSES	
Yes	29.03%	18
No	59.68%	37
Unsure	11.29%	7
TOTAL		62

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

Answered: 61 Skipped: 2

ANSWER CHOICES	AVERAGE NUMBER	TOTAL NUMBER	RESPONSES
	55	3,375	61
Total Respondents: 61			

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

Answered: 59 Skipped: 4

ANSWER CHOICES	AVERAGE NUMBER	TOTAL NUMBER	RESPONSES
	35	2,038	59
Total Respondents: 59			

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

Answered: 60 Skipped: 3

ANSWER CHOICES	AVERAGE NUMBER	TOTAL NUMBER	RESPONSES
	42	2,510	60
Total Respondents: 60			

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

Answered: 60 Skipped: 3

ANSWER CHOICES	AVERAGE NUMBER	TOTAL NUMBER	RESPONSES
	28	1,691	60
Total Respondents: 60			

Q14 Do you feel public understanding of your condition is:

Answered: 59 Skipped: 4

ANSWER CHOICES	AVERAGE NUMBER	TOTAL NUMBER	RESPONSES
	15	913	59
Total Respondents: 59			

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

Answered: 59 Skipped: 4

ANSWER CHOICES	AVERAGE NUMBER	TOTAL NUMBER	RESPONSES
	19	1,130	59
Total Respondents: 59			

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

Answered: 60 Skipped: 3

ANSWER CHOICES	RESPONSES	
Yes	20.00%	12
No	65.00%	39
I tried something but stopped using it	15.00%	9
TOTAL		60

Q17 If 'Yes', what are they called?

Answered: 11 Skipped: 52

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

Answered: 17 Skipped: 46

ANSWER CHOICES	RESPONSES	
Too difficult to use	11.76%	2
It was boring	5.88%	1
It seemed ineffective	58.82%	10
I'm worried about how my personal health data might be used	29.41%	5
Other (please specify)	17.65%	3
Total Respondents: 17		

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

Answered: 59 Skipped: 4

ANSWER CHOICES	RESPONSES	
Yes	25.42%	15
No	74.58%	44
TOTAL		59

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

Answered: 43 Skipped: 20

ANSWER CHOICES	RESPONSES	
Yes	74.42%	32
No	25.58%	11
TOTAL		43

Q21 Are you a member of a patient organisation?

Answered: 59 Skipped: 4

ANSWER CHOICES	RESPONSES	
Yes	33.90%	20
No	64.41%	38
In the past, but not now	1.69%	1
TOTAL		59

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

Answered: 35 Skipped: 28

ANSWER CHOICES	RESPONSES	
Yes	60.00%	21
No	40.00%	14
TOTAL		35

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: 53 Skipped: 10

	1	2	3	4	5	6	7	8	TOTAL	SCORE
Access to education	5.66% 3	7.55% 4	5.66% 3	5.66% 3	13.21% 7	13.21% 7	26.42% 14	22.64% 12	53	3.28
Relationships and sexual health	9.43% 5	7.55% 4	3.77% 2	15.09% 8	16.98% 9	7.55% 4	16.98% 9	22.64% 12	53	3.74
Access to employment	13.21% 7	9.43% 5	5.66% 3	11.32% 6	11.32% 6	22.64% 12	13.21% 7	13.21% 7	53	4.15
Stigma surrounding brain disease	15.09% 8	9.43% 5	13.21% 7	13.21% 7	15.09% 8	13.21% 7	13.21% 7	7.55% 4	53	4.66
Cost of medication/treatment	5.66% 3	26.42% 14	18.87% 10	3.77% 2	13.21% 7	11.32% 6	13.21% 7	7.55% 4	53	4.83
Depression / anxiety	22.64% 12	5.66% 3	15.09% 8	18.87% 10	9.43% 5	9.43% 5	3.77% 2	15.09% 8	53	4.94
Isolation	9.43% 5	16.98% 9	22.64% 12	16.98% 9	11.32% 6	11.32% 6	3.77% 2	7.55% 4	53	5.09
Access to medication/treatment	18.87% 10	16.98% 9	15.09% 8	15.09% 8	9.43% 5	11.32% 6	9.43% 5	3.77% 2	53	5.30