SURVEY OF YOUNG EUROPEANS WITH NEUROLOGICAL CONDITIONS

JULY 2018

EFNA
EUROPEAN FEDERATION OF NEUROLOGICAL ASSOCIATIONS

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- Myalgic Encephalomyelitis (ME)
- Migraine
- Chronic Pain
- Epilepsy
- Restless Legs Syndrome (RLS)
- Dystonia
- ADHD

FOR MORE INFORMATION PLEASE VISIT EFNA.NET

OR EMAIL COMMUNICATIONS@EFNA.NET

ABOUT THIS SURVEY

EFNA represents 20 European and International associations across a wide variety of neurological disease areas, such as multiple sclerosis, epilepsy, migraine and ADHD. Consensus among our members is that young people are currently under-represented in their associations. It is also felt that the issues facing young people affected by brain and brain-related disorders are not getting the public or political attention they should.

Those living with chronic illness face a number of additional burdens as young people. Often they are unable to complete their education, unable to take a place in the workforce, fear they will not find a romantic partner or have to watch their peers participate in activities they cannot access.

Comorbidity between neurological diseases and mental health disorders such as depression and anxiety is common. These comorbidities increase disease burden and stigma – issues acknowledged across our membership.

For these reasons EFNA has chosen to focus attention on young neurology patients during 2018.

To best assess the issues that should be explored as part of this work, EFNA conducted a pan-European survey of 18 – 35 year olds living with neurological disorders. The survey explores problems faced by this age group, as well as their feelings around levels of understanding of their disorder and their engagement in advocacy work or patient groups.

To gain a further insight into the following findings and develop next steps, EFNA will host an autumn workshop for 18-35 year olds with neurological disorders, from November 19th to 21st, in Brussels.

Our goal is to create a programme that empowers these young people to become advocates for their own disease areas. Development of this programme will see a group of young adults exposed to new ideas and new technologies and empowered to engage with patient groups and the wider community to advocate for the issues of most importance to them.

The title of this workshop will be: 'Patient Advocacy in the Digital World'. Interestingly, the survey showed that less than 20% of young patients use digital tools in the management and treatment of their conditions. However, as the EU focus moves more to digital health, we want to explore the challenges and opportunities that digital health solutions can bring to those living with neurological disorders.

For more on the survey or upcoming event, see efna.net or contact communications@efna.net.

SUMMARY

Between March 12th and May 15th 2018, 1368 responses to the survey were received from 39 countries.

Almost 80% of the respondents were female, with the majority of the responses coming from the below disease areas:

- Multiple Sclerosis
- Myalgic Encephalomyelitis
- Chronic Pain
- Migraine

Interestingly, all of the aforementioned conditions are largely 'invisible illnesses' with symptoms such as pain and fatigue featuring prominently.

It is no surprise, therefore, that two of the biggest issues for respondents are 'isolation' and 'stigma'. This could be attributed to the lack of public understanding of brain disorders. Overall, respondents placed understanding of both brain disorders (in general) and their conditions (specifically) at 2.5 – on a scale of 1-10, with 10 being full understanding. A lack of understanding was also clearly shown amongst family, friends and employers.

Interestingly, the top ranked issue was 'access to medication/treatment'. This is despite the fact that over 70% of respondents take prescribed medication, and just under 70% see a specialist/ neurologist. However, when asked what changes could improve the lives of respondents, many listed: a cure, more effective medication or medication with fewer side-effects. This seems to suggest that although these young patients have access to treatment it is often not optimal.

Therefore, the need for increased advocacy and awareness is clear.

Encouragingly, although almost two-thirds of the respondents had never taken part in an awareness campaign, approximately the same number indicated that they would be interested in doing so. Similarly, although the majority were not a member of a patient organisation, most were interested in learning more about how they could get involved.

We hope that, in partnership, we can take these findings and improve the quality of life of young people living with neurological disorder.

KEY FINDINGS

THE BIGGEST ISSUES

These are the biggest issues facing 18 - 35 year olds living with neurological disorders in Europe today, according to our survey.

2. ISOLATION

1. ACCESS TO MEDICATION/TREATMENT

STIGMA 3.

EDUCATION

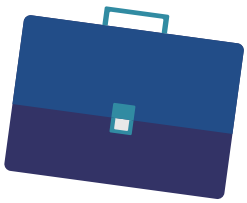
16% of respondents have obtained a Masters Degree

MS: 22%
ME: 8%
Migraine: 14%
Chronic pain: 11%
Epilepsy: 7%

EMPLOYMENT

34% of respondents are in full-time employment

MS: 43%
ME: 8%
Migraine: 22%
Chronic pain: 16%
Epilepsy: 37%



MEDICATION

72% of respondents take prescribed medication for their condition

MS: 90%
ME: 41%
Migraine: 70%
Chronic pain: 63%
Epilepsy: 95%

SPECIALIST CARE

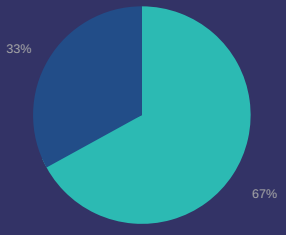
67% of respondents are under the care of a specialist doctor or neurologist

MS: 95%
ME: 19%
Migraine: 45%
Chronic pain: 43%
Epilepsy: 95%

ENGAGEMENT AND ADVOCACY

38% are members of patient organisations

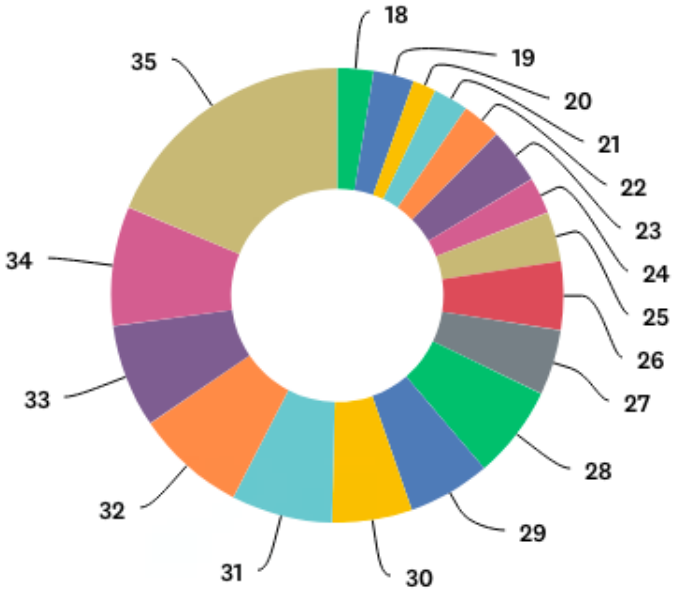
58% are interested in learning more about patient organisations



67% are interested in taking part in awareness raising activities

RESULTS OF THE SURVEY

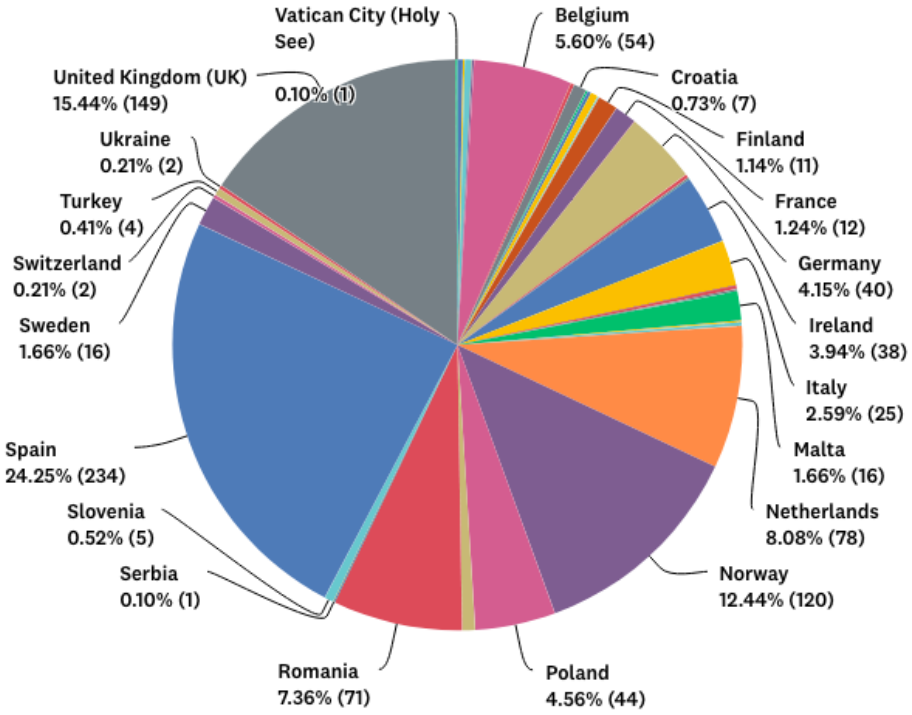
Q1. What age are you?



Q2. What is your gender?

Male - 20% Female - 79.07% Other - .52%

Q3. Where do you live?



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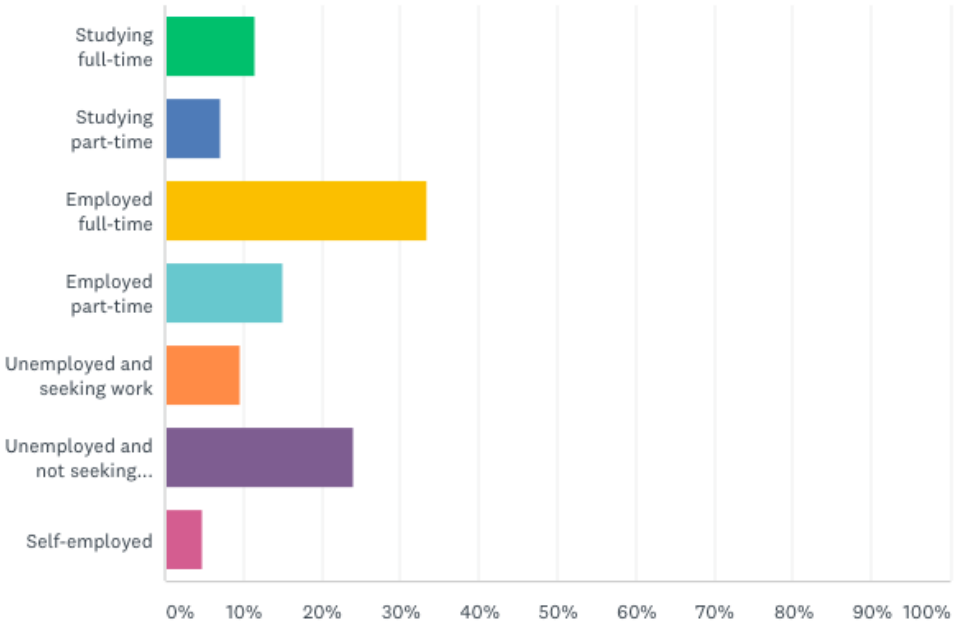
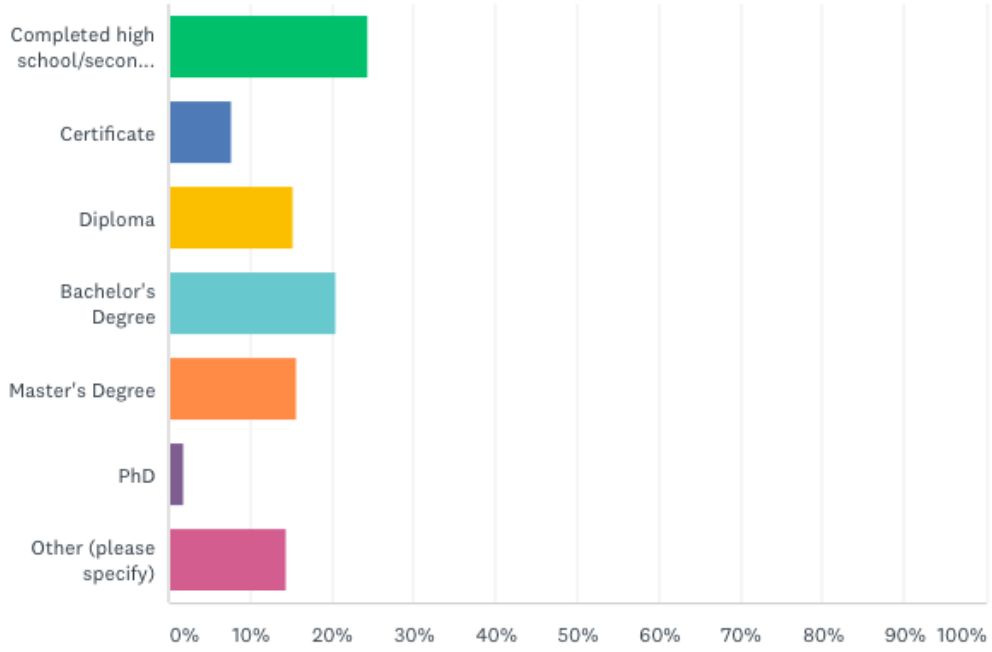
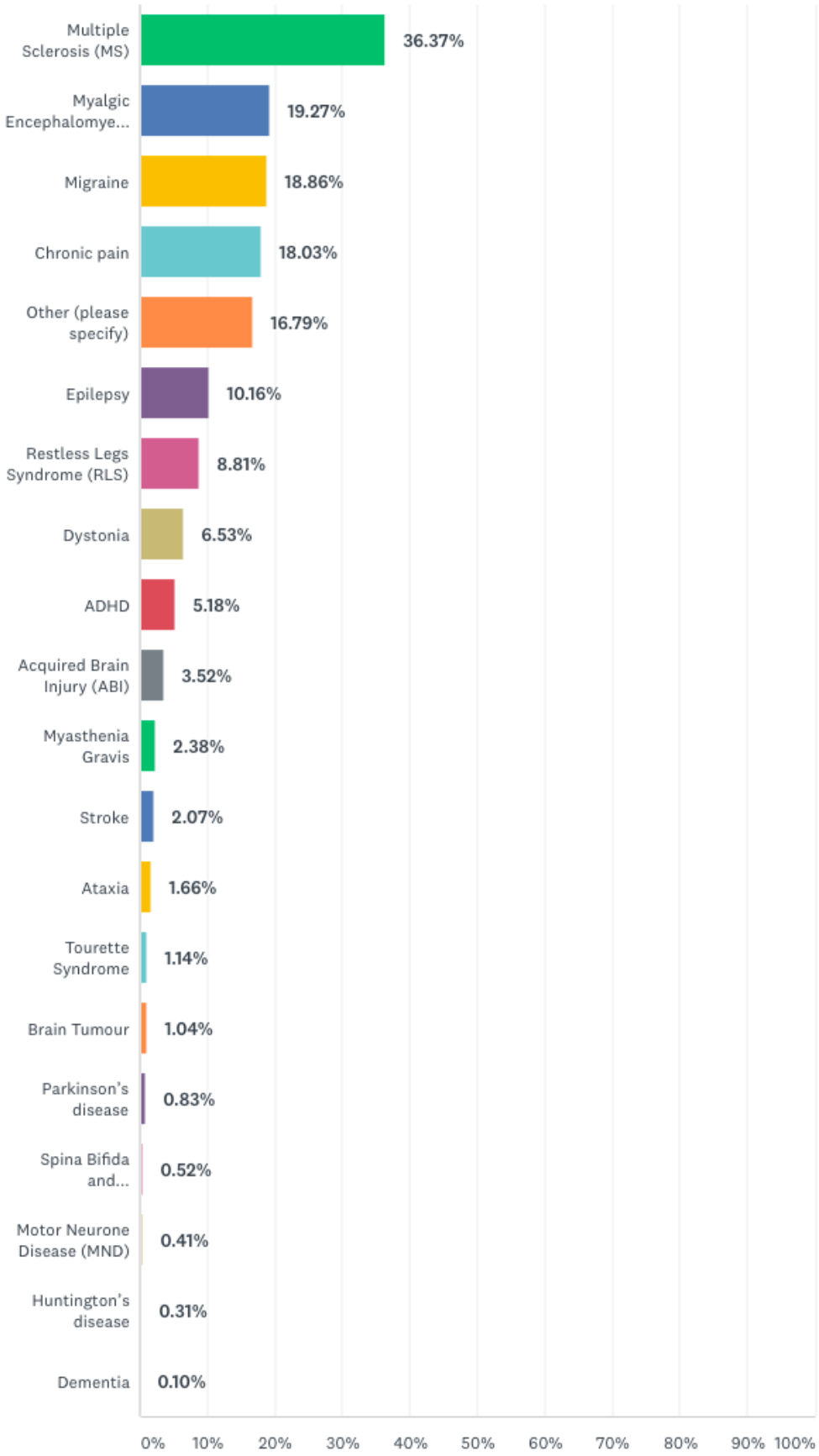
Q4. Are you currently...



Q5. What level of education have you achieved so far?



Q6. What neurological disorder(s) are you affected by?



Q7. **Do you take prescribed medication for the above?**

Yes - 71.92% No - 20.88% Previously, but not now - 7.20%

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

Yes - 67.12% No - 22.34% Previously, but not now - 10.54%

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

Yes - 35.00% No - 56.15% Unsure - 8.85%

Q10. **On a scale of 1 - 10, how well do you feel your family understand your condition?**

5.7 / 10

Q11. **On a scale of 1 - 10, how well do you feel your friends understand your condition?**

4.3 / 10

Q12. **On a scale of 1 - 10, how comfortable would you feel discussing your brain disorder with a new friend?**

5.1 / 10

Q13. **On a scale of 1 - 10, how comfortable would you feel discussing your brain disorder with an employer?**

3.4 / 10

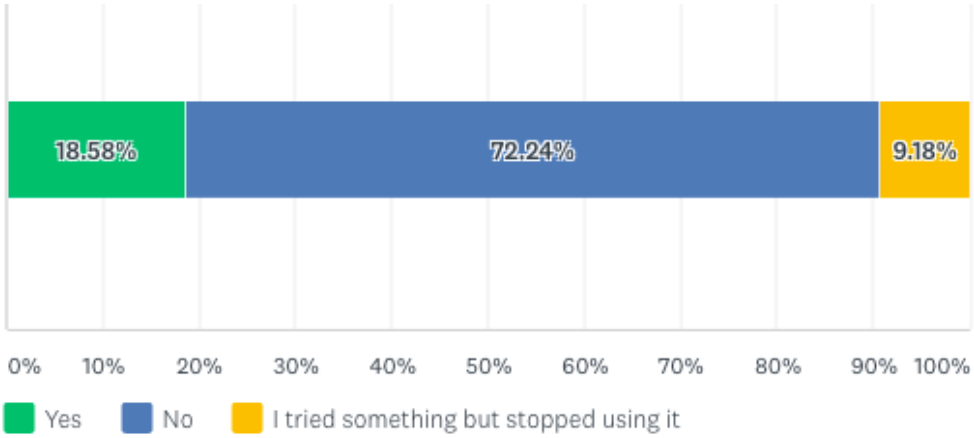
Q14. **On a scale of 1 - 10, how do you rate public understanding of your condition?**

2.5 / 10

Q15. **On a scale of 1 - 10, how do you rate public understanding of brain conditions in general?**

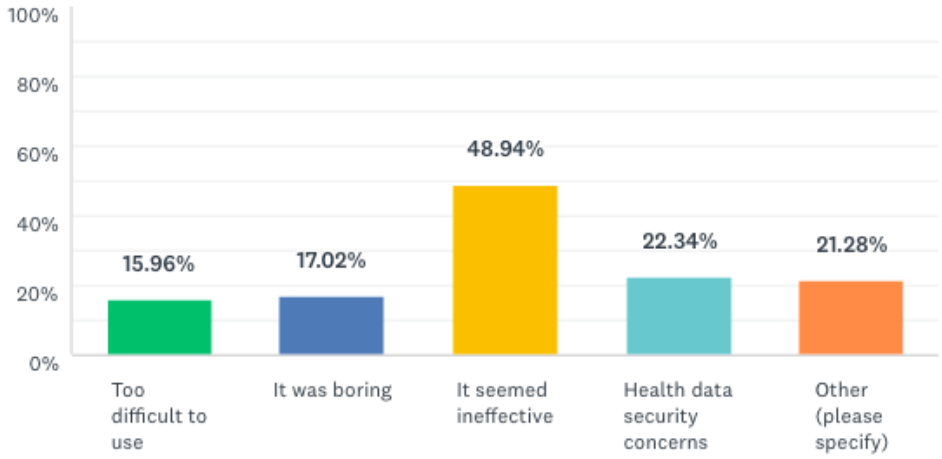
2.5 / 10

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



Q17. **If 'Yes', what are they called?**

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



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

Yes - 35.14% No - 64.86%

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

Yes - 66.96% No - 33.04%

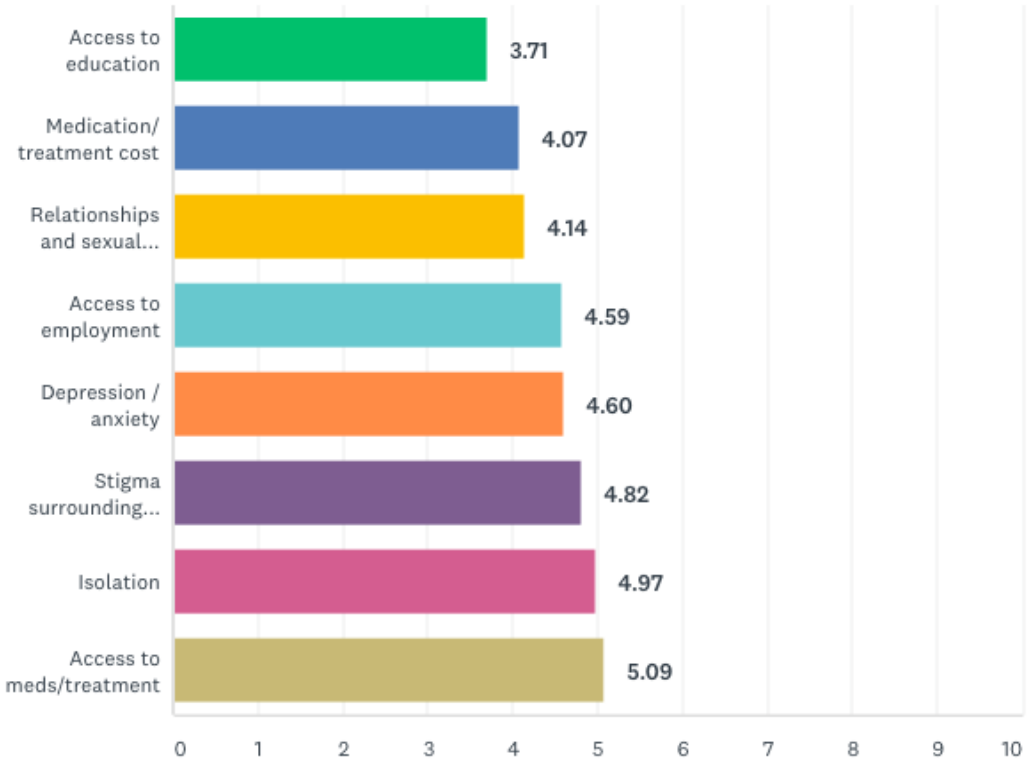
Q21. **Are you a member of a patient organisation?**

Yes - 37.73% No - 58.67% In the past but now now - 3.60%

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

Yes - 58.21% No - 41.79%

Q23. **Patient organisations need to know about the issues that affect you most as a young person with a neurological condition. Please rank the issues below:**



Q24. Please tell us a little bit about any challenges you face in your daily life:

For a complete list of responses to this question please click here.
The word cloud below is made up of the most important words/phrases to emerge, based on frequency of use.

Q25. What changes could improve life for you?

For a complete list of responses to this question please click here.
The word cloud below is made up of the most important words/phrases to emerge, based on frequency of use.

FOR THE COMPLETE SURVEY RESULTS IN TEXT FORMAT PLEASE CLICK HERE.

RESPONSES BY DISEASE AREA

A complete list of results is available for disease areas with more than 50 responses to the survey:

- Multiple Sclerosis (MS)
- Myalgic Encephalomyelitis (ME)
- Migraine
- Chronic Pain
- Epilepsy
- Restless Legs Syndrome (RLS)
- Dystonia
- ADHD

"Help finding employment"

"Financial Support"

"Less stigma around my condition"

"Flexible working conditions"

"Help with getting out and about more"

"For doctors to believe in me and the severity of my illness"

"Better understanding from doctors"

"Shorter commute to work"

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