

## IBE Epilepsy and Cognitive Function Survey

### Summary of results

<b>Demographics</b>	
Total respondents	425 (200 male; 223 female)
Countries surveyed	Belgium (58, 14%); Malta (52, 12%); Ireland (94, 22%); Scotland (149, 35%); Denmark (72, 17%)
Time on medication	Mean = 18.3 (SD = 14.21)

#### **Topline results:**

##### ***Treatment characteristics:***

- 95% of all respondents are currently taking medication for their epilepsy
- 59% of all respondents are taking multiple medications and 40% on monotherapy

##### ***Cognitive function:***

- 44% of respondents indicated 'very much' or 'moderately' when asked if they experienced difficulties learning something new
- 45% of respondents indicated 'very much' or 'moderately' when asked if they experienced slowness of thought
- 59% of respondents indicated 'very much' or 'moderately' when asked if they experienced sleepiness/tiredness
- 48% of respondents indicated 'very much' or 'moderately' when asked if they experienced lethargy/sluggishness

##### ***Relationship between cognitive function and AEDs:***

- A total of 56% of patients associated their cognitive impairment with their epilepsy medication – 14% of respondents stated that their cognitive problems were related to medication alone and a further 42% stated that effects were due to a combination of their condition and the medication they were taking

##### ***Impact on QoL:***

- When asked if the effects experienced have had a noticeable impact on work, 50% of respondents stated 'very much' or 'moderately'
- When asked if the effects experienced have had a noticeable impact on education, 45% of respondents stated 'very much' or 'moderately'
- When asked if the effects experienced have had a noticeable impact on family and relationships, 50% of respondents stated 'very much' or 'moderately'
- When asked if the effects experienced have had a noticeable impact on leisure pursuits, 46% of respondents stated 'very much' or 'moderately'
- 63% of respondents stated that effects experienced had prevented them doing a particular activity or achieving a goal (examples reported included following their chosen career, staying on in education and obtaining a driving licence)

- 61% of respondents stated that they had asked a healthcare professional if cognitive side effects can be reduced or improved
- Length of time on treatment did not relate to whether respondents sought healthcare professional advice on cognitive side effects

***Ideal treatment (open question)***

- When asked what side effects respondents would most want to avoid if they could design their own treatment, the most frequent responses were (>5%):
  - Sleepiness / tiredness (38%)
  - Memory problems (16%)
  - Lethargy / sluggishness (13%)
  - Weight gain / appetite (8%)
  - Difficulty paying attention (7%)
  - Slowness of thought (6%)
  - Dizziness / balance problems (6%)