IBE Epilepsy and Cognitive Function Survey

Summary of results

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