

### Supplemental File 3: CWE Perspectives on Communicating about Epilepsy

| I usually talk to my Mum or Dad about epilepsy when...            | N  | Really true for me | Sort of true for me | Not at all true for me | Does not apply, I never talk to my Mum or Dad about epilepsy  |
|---|----|--------------------|---------------------|------------------------|---|
| I have a seizure  | 44 | 59.1%              | 31.8%               | 6.8%                   | 2.3%  |
| I take my medication  | 45 | 40%                | 40%                 | 20%                    | 0%  |
| My medication is causing me difficulties                          | 44 | 54.5%              | 22.7%               | 22.7%                  | 0%  |
| I have a question about epilepsy                                  | 45 | 51.1%              | 44.4%               | 4.4%                   | 0%  |
| I have a hospital appointment coming up/have recently had one     | 45 | 60%                | 35.6%               | 4.4%                   | 0%  |
| I cannot take part in an activity because of my epilepsy          | 45 | 33.3%              | 26.7%               | 40%                    | 0%  |
| I am worried/upset  | 45 | 40%                | 26.7%               | 33.3%                  | 0%  |
| I need support  | 45 | 35.6%              | 22.2%               | 42.2%                  | 0%  |
| When I talk to my Mum or Dad about epilepsy, we talk about...     | N  | Really true for me | Sort of true for me | Not at all true for me | Does not apply, I never talk to my Mum or Dad about epilepsy  |
| What epilepsy is  | 45 | 33.3%              | 42.2%               | 24.4%                  | 0%  |
| How I feel about having epilepsy                                  | 45 | 33.3%              | 44.4%               | 22.2%                  | 0%  |
| What happens when I have a seizure (e.g. – what I look like)      | 45 | 53.3%              | 33.3%               | 13.3%                  | 0%  |
| My medication   | 45 | 53.3%              | 42.2%               | 4.4%                   | 0%  |
| Medication side effects   | 45 | 44.4%              | 24.4%               | 31.1%                  | 0%  |
| My hospital appointments  | 45 | 51.1%              | 48.9%               | 0%                     | 0%  |
| Things I cannot take part in because of my epilepsy               | 45 | 33.3%              | 28.9%               | 37.8%                  | 0%  |
| Whether my seizures are controlled or not                         | 45 | 40%                | 22.2%               | 37.8%                  | 0%  |
| Whether I will grow out of my epilepsy                            | 45 | 48.9%              | 33.3%               | 17.8%                  | 0%  |
| I talk to my Mum or Dad about my epilepsy because...              | N  | Really true for me | Sort of true for me | Not at all true for me | Does not apply, I never talk to my Mum or Dad about epilepsy  |
| I don't want to feel different                                    | 45 | 22.2%              | 31.1%               | 46.7%                  | 0%  |
| I want to know what I should do if I have a seizure               | 45 | 33.3%              | 28.9%               | 37.8%                  | 0%  |
| It helps me to deal with certain situations                       | 45 | 28.9%              | 40%                 | 31.1%                  | 0%  |
| I want to know a lot about my epilepsy                            | 45 | 35.6%              | 37.8%               | 26.7%                  | 0%  |
| I don't want to keep secrets about my epilepsy                    | 45 | 44.4%              | 26.7%               | 28.9%                  | 0%  |
| I don't talk to my Mum or Dad about my epilepsy because...        | N  | Really true for me | Sort of true for me | Not at all true for me | Does not apply, I always talk to my Mum or Dad about epilepsy |
| I don't want to feel different                                    | 44 | 13.6%              | 15.9%               | 56.8%                  | 13.6%   |
| I don't want to worry my Mum or Dad                               | 45 | 20%                | 15.6%               | 51.1%                  | 13.3%   |
| I don't want my Mum or Dad to think I am looking for attention    | 44 | 11.4%              | 18.2%               | 56.8%                  | 13.6%   |
| If I talk to my Mum or Dad they might not let me go to things     | 45 | 15.6%              | 17.8%               | 53.3%                  | 13.3%   |
| My Mum or Dad will make a big deal about it                       | 45 | 13.3%              | 13.3%               | 60%                    | 13.3%   |
| Do any of the following things make it helpful or challenging for |    | This helps         | This makes it       |                        |   |

| me to talk to my Mum or Dad about my epilepsy?             | N  | me    | difficult | This makes no difference  |
|--|----|-------|-----------|---|
| How much I usually talk to my Mum or Dad about things      | 45 | 44.4% | 6.7%      | 48.9%   |
| The amount of time that I have had epilepsy                | 45 | 35.6% | 11.1%     | 53.3%   |
| How much I know about my epilepsy                          | 45 | 48.9% | 13.3%     | 37.8%   |
| How often I have seizures                                  | 45 | 33.3% | 24.4%     | 42.2%   |
| When epilepsy is on the T.V. or radio                      | 45 | 37.8% | 6.7%      | 55.6%   |
| How I feel about my epilepsy                               | 45 | 37.8% | 26.7%     | 35.6%   |
| Talking about epilepsy with my Mum or Dad makes me feel... | N  | Yes   | No        | Does not apply, I never talk to my Mum or Dad about my epilepsy |
| Happy  | 44 | 54.5% | 45.5%     | 0%  |
| Sad  | 44 | 27.3% | 72.7%     | 0%  |
| Worried  | 44 | 31.8% | 68.2%     | 0%  |
| Brave  | 44 | 52.3% | 47.7%     | 0%  |
| Embarrassed  | 44 | 15.9% | 84.1%     | 0%  |
| Different  | 44 | 29.5% | 70.5%     | 0%  |
| Special  | 43 | 18.6% | 81.4%     | 0%  |