**Supplementary file 6: Factors affecting mental health related to living with a rare condition**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **1 (Strongly disagree) n (%)** | **2 (Disagree)** **n (%)** | **3 (Neutral)** **n (%)** | **4** **(Agree)** **n (%)** | **5 (Strongly agree)** **n (%)** | **Total** **n** |
| Lack of understanding about the condition amongst the general public | 15 (1.0) | 34 (2.3) | 96 (6.6) | 381 (26.1) | 932 (63.9) | 1,458 |
| Feeling uncertain about what the future holds | 25 (1.7) | 49 (3.3) | 116 (7.9) | 401 (27.3) | 878 (59.8) | 1,469 |
| Having to explain the condition to other people | 28 (1.9) | 89 (6.0) | 164 (11.1) | 435 (29.6) | 756 (51.4) | 1,472 |
| Lack of information about the condition | 31 (2.1) | 137 (9.5) | 184 (12.7) | 409 (28.2) | 687 (47.4) | 1,448 |
| Worrying information I have found online | 73 (5.2) | 197 (14.0) | 349 (24.7) | 331 (23.5) | 461 (32.7) | 1,411 |

**Data shown for patients and carers combined.**