**Supplementary file 5: Interactions with healthcare professionals and service access**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **1 (Strongly disagree) n (%)** | **2 (Disagree)**  **n (%)** | **3**  **(Neutral)**  **n (%)** | **4**  **(Agree)**  **n (%)** | **5**  **(Strongly agree)**  **n (%)** | **Total**  **n** |
| **Interactions with healthcare professionals** |  |  |  |  |  |  |
| Lack of awareness or understanding by healthcare professionals | 24 (1.6) | 53 (3.6) | 101 (6.8) | 366 (24.6) | 942 (63.4) | 1,486 |
| Not being believed or taken seriously by some healthcare professionals | 68 (47) | 101 (7.0) | 117 (8.1) | 350 (24.2) | 808 (56.0) | 1,444 |
| Being treated as a medical curiosity | 108 (7.5) | 259 (18.0) | 352 (24.6) | 344 (24.0) | 370 (25.8) | 1,433 |
| Conversations with some healthcare professionals | 52 (3.5) | 92 (6.2) | 148 (10.0) | 507 (34.1) | 688 (46.3) | 1,487 |
| **Access/coordination of services** |  |  |  |  |  |  |
| Trying to access services | 55 (3.7) | 93 (6.3) | 156 (10.5) | 430 (28.9) | 753 (50.6) | 1,487 |
| The way care is coordinated | 49 (3.3) | 72 (4.9) | 187 (12.7) | 368 (25.1) | 793 (54.0) | 1,469 |
| Accessing financial support e.g. disability living allowance | 47 (3.7) | 64 (5.1) | 192 (15.3) | 210 (16.7) | 741 (59.1) | 1,254 |
| Accessing other support e.g. social care, respite | 40 (3.0) | 85 (6.4) | 249 (18.9) | 293 (22.2) | 652 (49.4) | 1,319 |

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