**File G - DMD-QoL 27-item response distributions in the psychometric survey (N=102)**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **Response (%)** | | | | |
| **Item** | **1** | **2** | **3** | **4** | **NA** |
| I found it hard to get around | 19.61 | 45.10 | 15.69 | 19.61 | 0.00 |
| I found it hard to use my arms | 25.49 | 52.94 | 3.92 | 17.65 | 0.00 |
| I found It hard to use my hands | 41.18 | 44.12 | 7.84 | 6.86 | 0.00 |
| I found it hard to use my fingers | 49.02 | 41.18 | 6.86 | 2.94 | 0.00 |
| I found it hard to eat | 57.84 | 27.45 | 4.90 | 6.86 | 2.94 |
| I found it hard to breathe | 81.37 | 12.75 | 2.94 | 1.96 | 0.98 |
| I was in pain | 37.25 | 49.02 | 11.76 | 1.96 | 0.00 |
| I felt tired | 3.92 | 60.78 | 29.41 | 5.88 | 0.00 |
| I found it hard to talk to people | 43.14 | 39.22 | 11.76 | 5.88 | 0.00 |
| I could take part in the things I wanted to | 5.88 | 50.00 | 25.49 | 16.67 | 1.96 |
| I did the things I enjoyed | 1.96 | 36.27 | 45.10 | 16.67 | 0.00 |
| I could do the things I wanted to by myself | 17.65 | 50.98 | 25.49 | 5.88 | 0.00 |
| I was happy with the people around me | 0.98 | 21.57 | 43.14 | 34.31 | 0.00 |
| I was happy with the people I had to help me | 2.94 | 19.61 | 35.29 | 41.18 | 0.98 |
| I could take part in things with my friends | 8.82 | 58.82 | 15.69 | 10.78 | 5.88 |
| I felt left out | 26.47 | 48.04 | 17.65 | 4.90 | 2.94 |
| I felt lonely | 26.47 | 54.90 | 16.67 | 1.96 | 0.00 |
| I liked the way I was treated by people | 0.98 | 34.31 | 35.29 | 28.43 | 0.98 |
| I felt good about myself | 4.90 | 32.35 | 44.12 | 15.69 | 2.94 |
| I felt good about my appearance | 5.88 | 40.20 | 26.47 | 25.49 | 1.96 |
| I felt worried | 14.71 | 60.78 | 17.65 | 5.88 | 0.98 |
| I felt embarrassed | 36.27 | 48.04 | 11.76 | 0.98 | 2.94 |
| I felt unhappy | 18.63 | 71.57 | 7.84 | 1.96 | 0.00 |
| I felt annoyed | 12.75 | 57.84 | 27.45 | 0.98 | 0.98 |
| I felt angry | 24.51 | 53.92 | 20.59 | 0.98 | 0.00 |
| I was worried about the future | 29.41 | 50.98 | 12.75 | 4.90 | 1.96 |
| I felt I could cope with things | 5.88 | 31.37 | 46.08 | 11.76 | 4.90 |

**Response levels**

1 = Never

2 = Sometimes

3 = A lot of the time

4 = All of the time

NA = ‘Prefer not to disclose’