**Supplemental Material**

**eTable 1: Estimated KIDSCREEN-27 scores, by motor function and SMA type**

|  |  |  |  |
| --- | --- | --- | --- |
|  | **Non-sitter** | **Sitter** | **Walker** |
| **Physical Wellbeing** | 35.41 (4.93) (28.13 to 38.47) | 40.22 (9.53) (30.57 to 49.63) | 48.3 (10.50) (38.47 to 59.36) |
| **Psychological Wellbeing** | 44.28 (3.83) (40.39 to 48.45) | 54.84 (16.97) (40.39 to 73.53) | 48.41 (8.07) (39.10 to 53.07) |
| **Parents** | 46.96 (8.85) (34.69 to 55.75) | 63.88 (10.57) (53.25 to 74.39) | 70.92 (6.00) (63.99 to 74.39) |
| **Peers** | 40.61 (11.76) (23.62 to 49.79) | 53.89 (12.14) (42.09 to 66.34) | 53.51 (11.43) (44.4 to 66.34) |
| **School** | 64.58 (7.41) (58.16 to 71.00) | 56.11 (6.06) (51.08 to 62.84) | 64.00 (6.50) (58.16 to 71.00) |
| **Total** | 48.24 (7.18) (40.24 to 57.29) | 63.11 (19.28) (45.67 to 83.81) | 67.34 (16.23) (51.36 to 83.81) |
|  |  |  |  |
|  | **SMA type I** | **SMA type II** | **SMA type III** |
| **Physical Wellbeing** | 49.63 (·) (49.63 to 49.63) | 34.83 (5.26) (28.13 to 40.45) | 45.85 (9.88) (38.47 to 59.36) |
| **Psychological Wellbeing** | 73.53 (·) (73.53 to 73.53) | 44.32 (4.85) (40.39 to 50.61) | 47.94 (6.65) (39.10 to 53.07) |
| **Parents** | 74.39 (·) (74.39 to 74.39) | 54.08 (6.34) (47.93 to 63.99) | 61.87 (18.77) (34.69 to 74.39) |
| **Peers** | 66.34 (·) (66.34 to 66.34) | 43.13 (11.65) (23.62 to 53.23) | 50.66 (10.94) (42.09 to 66.34) |
| **School** | 62.84 (·) (62.84 to 62.84) | 61.13 (9.35) (51.08 to 71.00) | 62.54 (6.06) (58.16 to 71.00) |
| **Total** | 83.81 (·) (83.81 to 83.81) | 50.56 (8.10) (40.24 to 59.85) | 61.93 (17.12) (45.67 to 83.81) |

*Note: Data reported as mean (SD) (range) unless otherwise stated. Spinal muscular atrophy (SMA).*

**eTable 2: Estimated KINDL total score, by motor function and SMA type**

|  |  |  |  |
| --- | --- | --- | --- |
|  | **Non-sitter** | **Sitter** | **Walker** |
| **Physical role** | · | 81.25 (8.84) (75.00 to 87.50) | · |
| **Emotional role** | · | 78.13 (22.10) (62.50 to 93.75) | · |
| **Self-esteem** | · | 71.88 (4.42) (68.75 to 75.00) | · |
| **Family** | · | 62.50 (8.84) (56.25 to 68.75) | · |
| **Friends** | · | 78.13 (13.26) (68.75 to 87.50) | · |
| **School** | · | 90.63 (4.42) (87.50 to 93.75) | · |
| **Chronic disease** | · | 87.50 (4.82) (83.33 to 91.67) | 69.44 (12.73) (58.33-83.33) |
| **Total** | · | 75.00 (3.07) (70.83 to 78.13) | 68.05 (19.69) (45.83-83.33) |
|  |  |  |  |
|  | **SMA type I** | **SMA type II** | **SMA type III** |
| **Physical role** | 75.00 (·) (75.00 to 75.00) | 87.50 (·) (87.50 to 87.50) | · |
| **Emotional role** | 93.75 (·) (93.75 to 93.75) | 62.50 (·) (62.50 to 62.50) | · |
| **Self-esteem** | 68.75 (·) (68.75 to 68.75) | 75.00 (·) (75.00 to 75.00) | · |
| **Family** | 56.25 (·) (56.25 to 56.25) | 68.75 (·) (68.75 to 68.75) | · |
| **Friends** | 87.50 (·) (87.50 to 87.50) | 68.75 (·) (68.75 to 68.75) | · |
| **School** | 87.50 (·) (87.50 to 87.50) | 93.75 (·) (93.75 to 93.75) | · |
| **Chronic disease** | 87.50 (5.90) (83.33 to 91.67) | 86.11 (4.82) (83.33 to 91.67) | 62.50 (5.90) (58.33 to 66.67) |
| **Total** | 76.57 (2.21) (75.00 to 78.13) | 76.73 (6.28) (70.83 to 83.33) | 60.42 (20.63) (45.83 to 75.00) |

*Note: Data reported as mean (SD) (range) unless otherwise stated. Domain scores were only available for the KID version of KINDL. Spinal muscular atrophy (SMA).*

**eTable 3: Estimated PedsQL 3.0 NMM scores, by motor function and SMA type**

|  |  |  |  |
| --- | --- | --- | --- |
|  | **Non-sitter** | **Sitter** | **Walker** |
| **About my neuromuscular disease** | 59.25 (13.07) (40.00 to 69.00) | 73.29 (22.81) (29.00 to 97.00) | 83.33 (12.75) (65.00 to 99.00) |
| **Communication** | 62.50 (53.03) (25.00 to 100.00) | 100.00 (0.00) (100.00 to 100.00) | 96.00 (5.66) (92.00 to 100.00) |
| **About our family resources** | 52.50 (38.89) (25.00 to 80.00) | 81.67 (12.58) (70.00 to 95.00) | 92.50 (10.61) (85.00 to 100.00) |
| **Total** | 58.00 (15.17) (40.00 to 72.00) | 74.43 (22.13) (29.00 to 94.00) | 83.83 (13.12) (65.00 to 99.00) |
|  |  |  |  |
|  | **SMA type I** | **SMA type II** | **SMA type III** |
| **About my neuromuscular disease** | 71.33 (36.94) (29.00 to 97.00) | 67.25 (14.03) (40.00 to 85.00) | 83.00 (13.16) (65.00 to 99.00) |
| **Communication** | 100.00 (·) (100.00 to 100.00) | 81.25 (37.5) (25.00 to 100.00) | 96.00 (5.66) (92.00 to 100.00) |
| **About our family resources** | 80.00 (·) (80.00 to 80.00) | 67.50 (30.14) (25.00 to 95.00) | 92.50 (10.61) (85.00 to 100.00) |
| **Total** | 70.33 (35.92) (29.00 to 94.00) | 68.00 (15.71) (40.00 to 89.00) | 83.50 (13.53) (65.00 to 99.00) |

*Note: Data reported as mean (SD) (range) unless otherwise stated. Spinal muscular atrophy (SMA).*

**eTable 4: Estimated EQ-5D-5L utilities and VAS scores, by motor function and SMA type**

|  |  |  |  |
| --- | --- | --- | --- |
|  | **Non-sitter** | **Sitter** | **Walker** |
| **EQ-5D-5L utility** | 0.35 (0.06) (0.30 to 0.39) | 0.37 (0.06) (0.31 to 0.42) | 0.99 (0.02) (0.97 to 1.00) |
| **VAS score** | 87.50 (3.54) (85.00 to 90.00) | 64.67 (25.01) (40.00 to 90.00) | 90.00 (0.00) (90.00 to 90.00) |
|  |  |  |  |
|  | **SMA type I** | **SMA type II** | **SMA type III** |
| **EQ-5D-5L utility** | 0.31 (0.00) (0.31 to 0.31) | 0.37 (0.05) (0.30 to 0.42) | 0.99 (0.02) (0.97 to 1.00) |
| **VAS score** | 90.00 (·) (90.00 to 90.00) | 69.75 (22.81) (40.00 to 90.00) | 90.00 (0.00) (90.00 to 90.00) |

*Note: Data reported as mean (SD) (range) unless otherwise stated. Spinal muscular atrophy (SMA).*

**eTable 5: Estimated HUI (Mark III) utilities, by motor function and SMA type**

|  |  |  |  |
| --- | --- | --- | --- |
|  | **Non-sitter** | **Sitter** | **Walker** |
| **HUI Mark III utility** | 0.23 (0.27) (0.08 to 0.63) | 0.21 (0.20) (-0.02 to 0.34) | 0.96 (0.08) (0.87 to 1.00) |
|  |  |  |  |
|  | **SMA type I** | **SMA type II** | **SMA type III** |
| **HUI Mark III utility** | -0.02 (·) (-0.02 to -0.02) | 0.19 (0.12) (0.08 to 0.34) | 0.88 (0.17) (0.63 to 1.00) |

*Note: Data reported as mean (SD) (range) unless otherwise stated. Spinal muscular atrophy (SMA).*