|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  |  | **Entry Item** | | | | | | |
|  |  | **0 (N=1)** | **1 (N=124)** | **2 (N=47)** | **3 (N=79)** | **4 (N=28)** | **5 (N=49)** | **6 (N=29)** |
| **Baseline** | **CS treatment** |  |  |  |  |  |  |  |
| NO | 1 (100%) | 66 (53.2%) | 17 (36.2%) | 15 (19.0%) | 0 (0%) | 1 (2.0%) | 2 (6.9%) |
| YES | 0 (0%) | 58 (46.8%) | 30 (63.8%) | 64 (81.0%) | 28 (100%) | 48 (98.0%) | 27 (93.1%) |
| **Age** |  |  |  |  |  |  |  |
| Mean (95% CI) | 24.93  (16.57 - 33.29) | 19.08  (18.32 - 19.84) | 17.46  (16.59 - 18.34) | 16.42  (15.63 - 17.22) | 14.89  (13.86 - 15.93) | 14.02  (13.12 - 14.92) | 14.26  (13.15 - 15.36) |
| **Total PUL 2.0 score** |  |  |  |  |  |  |  |
| Mean (95% CI) | 1  (-8.22-10.22) | 11.16  (10.21-12.11) | 15.29  (13.98-16.61) | 19.31  (18.23-20.39) | 28.31  (26.64-29.98) | 32.13  (30.8-33.46) | 35.98  (34.33-37.62) |
| **12 months changes from baseline** | **TOTAL** |  |  |  |  |  |  |  |
| Mean (95% CI) | 0  (-5.72 - 5.72) | -0.84  (-1.34 - -0.34) | -0.7  (-1.88 - 0.48) | -2.05  (-2.68 - -1.43) | -5.07  (-6.18 - -3.96) | -4.34  (-5.16 - -3.53) | -4.87  (-5.92 - -3.82) |
| **SHOULDER** |  |  |  |  |  |  |  |
| Mean (95% CI) | 0  (-2.7 - 2.7) | -0.02  (-0.27 - 0.23) | 0.02  (-0.38 - 0.43) | -0.02  (-0.34 - 0.28) | -3.15  (-3.69 - -2.61) | -2.1  (-2.51 - -1.7) | -3.02  (-3.53 - -2.5) |
| **ELBOW** |  |  |  |  |  |  |  |
| Mean (95% CI) | 0  (-3.7 - 3.7) | -0.4  (-0.72 - -0.08) | -0.53  (-1.06 - -0.01) | -1.57  (-1.97 - -1.16) | -1.94  (-2.66 - -1.22) | -2.01  (-2.53 - -1.48) | -1.66  (-2.34 - -0.98) |
| **DISTAL** |  |  |  |  |  |  |  |
| Mean (95% CI) | 0  (-2.13 - 2.13) | -0.44  (-0.63 - -0.26) | -0.26  (-0.57 - 0.03) | -0.38  (-0.61 - -0.15) | -0.07  (-0.49 - 0.33) | -0.2  (-0.5 - 0.1) | -0.28  (-0.67 - 0.1) |
| **24 months changes from baseline** | **TOTAL** |  |  |  |  |  |  |  |
| Mean (95% CI) | 0  (-7.21 - 7.21) | -1.78  (-2.49 - -1.07) | -2.06  (-3.17 - -0.94) | -3.82  (-4.68 - -2.96) | -8.47  (-9.91 - -7.04) | -8.68  (-9.77 - -7.59) | -9.86  (-11.21 - -8.5) |
| **SHOULDER** |  |  |  |  |  |  |  |
| Mean (95% CI) | 0  (-3.24 - 3.24) | -0.01  (-0.34 - 0.31) | 0.13  (-0.34 - 0.6) | 0.05  (-0.33 - 0.45) | -4.34  (-4.96 - -3.72) | -4.75  (-5.23 - -4.27) | -6.14  (-6.74 - -5.54) |
| **ELBOW** |  |  |  |  |  |  |  |
| Mean (95% CI) | 0  (-4.48 - 4.48) | -0.71  (-1.13 - -0.3) | -1.37  (-2.04 - -0.7) | -2.98  (-3.5 - -2.46) | -3.61  (-4.5 - -2.72) | -3.65  (-4.31 - -2.98) | -3.37  (-4.21 - -2.53) |
| **DISTAL** |  |  |  |  |  |  |  |
| Mean (95% CI) | 0  (-3.03 - 3.03) | -1.07  (-1.35 - -0.78) | -0.71  (-1.16 - -0.25) | -0.83  (-1.18 - -0.47) | -0.44  (-1.04 - 0.16) | -0.28  (-0.73 - 0.17) | -0.49  (-1.06 - 0.07) |

**Supplementary table 1. Non ambulant population 12 and 24 months changes subdivided by PUL 2.0 entry item.**