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|  |  | **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.**