

**Table S4 - Utilities derived for chronic disease**

| Author, Year<br>Country             | Study<br>Design     | Condition                                                         | Interven-<br>tions | Setting                                                                                              | Mean (SD) Age                               | %<br>Males | Utility<br>Instrument | Baseline Utility                   |                            | End of Study Utility |           |
|-------------------------------------|---------------------|-------------------------------------------------------------------|--------------------|------------------------------------------------------------------------------------------------------|---------------------------------------------|------------|-----------------------|------------------------------------|----------------------------|----------------------|-----------|
|                                     |                     |                                                                   |                    |                                                                                                      |                                             |            |                       | N                                  | Mean (SD)                  | N                    | Mean (SD) |
| Children/ Adolescents               |                     |                                                                   |                    |                                                                                                      |                                             |            |                       |                                    |                            |                      |           |
| Janse et al.<br>2005<br>Netherlands | cross-<br>sectional | ALL, juvenile<br>chronic arthritis,<br>asthma, cystic<br>fibrosis | n/a                | tertiary pediatric<br>centers                                                                        | 8.5 (4.2)                                   | 48         | HUI 3                 | Parents: 279<br>Pediatricians: 279 | 0.80<br>0.93               | n/a                  | n/a       |
| Sung et al.<br>2004<br>Canada       | cross-<br>sectional | chronic<br>disease                                                | n/a                | oncology ward & outpatient<br>rheumatology, hemophilia,<br>or bone marrow<br>transplantation clinics | Patients: 13.7 (1.7)<br>Parents: 43.3 (4.7) | 55<br>18   | HUI 2                 | Patients: 22<br>Parents: 22        | 0.95 (0.07)<br>0.82 (0.22) | n/a                  | n/a       |
|                                     |                     |                                                                   |                    |                                                                                                      |                                             |            | HUI 3                 | Patients: 22<br>Parents: 22        | 0.92 (0.09)<br>0.79 (0.26) | n/a                  | n/a       |
|                                     |                     |                                                                   |                    |                                                                                                      |                                             |            | TTO                   | Patients: 22<br>Parents: 22        | 0.92 (0.11)<br>0.77 (0.31) | n/a                  | n/a       |

SD-standard deviation; n/a-not available; ALL-acute lymphoblastic leukemia