# SUPPLEMENTARY MATERIAL: Validation of a new glucocorticoid-specific patient reported outcome questionnaire (the Steroid PRO)

### Supplementary Table S1: Survey responses at Timepoint 1; full list of diseases

|  | n   |     |
|--|-----|-----|
| Adult-onset Still's disease  | 1   | 0%  |
| ANCA Vasculitis (NOS)  | 5   | 0%  |
| Ankylosing spondylitis   | 9   | 1%  |
| Aortitis   | 1   | 0%  |
| Behcet's disease   | 20  | 2%  |
| CNS Vasculitis   | 7   | 1%  |
| Cryoglobulinemia vasculitis  | 2   | 0%  |
| Enteropathic arthritis   | 2   | 0%  |
| Eosinophilic granulomatosis with polyangiitis (also known as Churg Strauss Vasculitis) | 34  | 3%  |
| Giant Cell Arteritis (also known as Temporal Arteritis)                                | 128 | 11% |
| Gout   | 3   | 0%  |
| Granulomatosis with polyangiitis (Wegener's)   | 110 | 9%  |
| IgA/Henoch Schonlein   | 8   | 1%  |
| IgG4-related disease   | 1   | 0%  |
| Inflammatory arthritis (NOS)   | 2   | 0%  |
| Inflammatory myositis (polymyositis or dermatomyositis)                                | 10  | 1%  |
| Juvenile inflammatory arthritis (JIA)  | 7   | 1%  |
| Large Vessel Vasculitis (NOS)  | 2   | 0%  |
| Leukocytoclastic vasculitis  | 1   | 0%  |
| Mast Cell Activation Disorder  | 1   | 0%  |
| Microscopic polyangiitis   | 24  | 2%  |

| Mixed connective tissue disease             | 20  | 2%  |
|---|-----|-----|
| Palindromic rheumatism                      | 4   | 0%  |
| Polyarteritis nodosa                        | 10  | 1%  |
| Polymyalgia rheumatica                      | 302 | 26% |
| Psoriatic arthritis                         | 21  | 2%  |
| Reactive arthritis                          | 10  | 1%  |
| Relapsing polychondritis                    | 3   | 0%  |
| Rheumatoid arthritis                        | 164 | 14% |
| Seronegative arthritis/spondyloarthropathy  | 8   | 1%  |
| Sjogren's syndrome                          | 31  | 3%  |
| Small vessel vasculitis (NOS)               | 11  | 1%  |
| Systemic Lupus Erythematosus (Lupus or SLE) | 66  | 6%  |
| Systemic sarcoidosis                        | 64  | 6%  |
| Systemic sclerosis (Scleroderma)            | 32  | 3%  |
| Takayasu arteritis                          | 18  | 2%  |
| Undifferentiated rheumatic disease          | 10  | 1%  |
| Urticarial vasculitis                       | 11  | 1%  |

NB: Participants were able to report multiple diseases

| Supplementary | Table S2: Survey | responses at 1 | Timepoint 1: p                      | participant ethnicities |
|---------------|------------------|----------------|-------------------------------------|-------------------------|
|               |                  |                | · · · · · • • • • • • • • • • • • • |                         |

|   | n   |     |
|---|-----|-----|
| English / Welsh / Scottish / Northern Irish / British | 693 | 73% |
| American  | 117 | 12% |
| Australian  | 41  | 4%  |
| Irish   | 18  | 2%  |
| American Indian / Alaska Native                       | 4   | 0%  |
| African   | 6   | 1%  |
| Black British   | 2   | 0%  |
| Chinese   | 4   | 0%  |
| Indian  | 3   | 0%  |
| Pakistani   | 2   | 0%  |
| Other ethnic background                               | 11  | 1%  |
| Other Asian background                                | 2   | 0%  |
| Other black background                                | 3   | 0%  |
| Other white background                                | 30  | 3%  |
| Prefer not to answer                                  | 10  | 1%  |
| Total completed responses                             | 946 |     |

|     |                           | 5 Category responses                             |  |          |        | 4 Category responses |   |          |       |          |        |    |          |
|-----|---------------------------|--|--|----------|--------|----------------------|---|----------|-------|----------|--------|----|----------|
|     |                           | (never=0,  | (never=0, rarely=1, sometimes=2, often=3 and always=4) |          |        |                      | (never=0, sometimes=1, often=2 and always=3)    |          |       |          |        |    |          |
| Seq | Item                      | Location   | SE   | FitResid | χ2     | DF                   | *p-value  | Location | SE    | FitResid | χ2     | DF | *p-value |
| 10  | Fatigue/ tiredness        | -0.76  | 0.037  | 1.76     | 14.865 | 9                    | 0.094708  | -0.864   | 0.042 | 2.298    | 13.763 | 9  | 0.131019 |
| 15  | Appearance changes        | -0.472   | 0.031  | 0.873    | 8.439  | 9                    | 0.490604  | -0.686   | 0.037 | 0.007    | 9.645  | 9  | 0.37999  |
| 16  | Clothes not fitting       | -0.269   | 0.031  | -0.036   | 2.197  | 9                    | 0.987949  | -0.428   | 0.037 | -0.853   | 5.141  | 9  | 0.821816 |
| 20  | Anger/ irritation         | 0.433  | 0.037  | 0.156    | 12.757 | 9                    | 0.173922  | 0.609    | 0.046 | -0.453   | 13.132 | 9  | 0.156715 |
| 23  | Anxiety                   | 0.482  | 0.036  | -0.26    | 6.628  | 9                    | 0.675758  | 0.618    | 0.046 | 0.03     | 6.268  | 9  | 0.712872 |
| 24  | Physical agitation        | 0.551  | 0.037  | 0.222    | 11.651 | 9                    | 0.233731  | 0.745    | 0.047 | 0.093    | 11.445 | 9  | 0.246463 |
| 26  | Clarity of thinking       | 0.663  | 0.037  | -0.438   | 23.113 | 9                    | 0.005948  | 0.818    | 0.048 | -0.928   | 18.706 | 9  | 0.027816 |
| 27  | Talking too much          | 1.068  | 0.038  | 2.272    | 23.364 | 9                    | 0.005431  | 1.271    | 0.052 | 0.322    | 10.53  | 9  | 0.309318 |
| 28  | Feeling upset             | -0.029   | 0.033  | -1.623   | 14.107 | 9                    | 0.118581  | -0.08    | 0.04  | -2.406   | 11.363 | 9  | 0.251663 |
| 29  | Extra medications         | -0.03  | 0.033  | 0.795    | 7.202  | 9                    | 0.616128  | -0.118   | 0.04  | -0.092   | 5.841  | 9  | 0.755673 |
| 30  | Long-term risks           | -0.951   | 0.037  | 1.684    | 7.884  | 9                    | 0.545882  | -1.032   | 0.041 | 2.233    | 6.741  | 9  | 0.664059 |
| 31  | Worrying about weight     | -0.773   | 0.034  | 1.229    | 12.082 | 9                    | 0.208727  | -0.99    | 0.039 | 0.974    | 5.111  | 9  | 0.824522 |
| 38  | Everyday responsibilities | -0.027   | 0.034  | -0.462   | 13.881 | 9                    | 0.126632  | -0.001   | 0.041 | -0.439   | 9.861  | 9  | 0.361824 |
| 39  | Being with other people   | 0.161  | 0.034  | 2.232    | 2.535  | 9                    | 0.979935  | 0.159    | 0.043 | 3.12     | 4.009  | 9  | 0.910832 |
| 40  | Joining in                | -0.048   | 0.036  | -2.123   | 20.561 | 9                    | 0.014751  | -0.019   | 0.043 | -2.088   | 24.372 | 9  | 0.003752 |
|     | Overall fit               | <b>χ2</b> (DF) 181.26(135); p=0.0049; PSI=0.8997 |  |          |        |                      | <b>χ2</b> (DF) 155.93 (135); p=0.105; PSI=0.877 |          |       |          |        |    |          |

#### Supplementary Table S3: Rasch Analysis with individual items, comparing 5 and 4 category response structure

Legends: SE, Standard error; DF, degree of freedom; FitResid, Fit residuals expected to be within -2.5 and 2.5 for model fit; \*p-value, χ2 probability, where >0.05 (>0.00125 for Bonferroni correction for 5 Category responses, >0.0033 for Bonferroni correction for 4 Category responses) suggests adequate fit to the model.

## Supplementary Table S4: Results of DIF analysis in the disease groups (IA, CTD/Vasculitis and GCA/PMR)

|                         | Main efj<br>(uniform | fects: Disea:<br>n DIF) | ир      | Interaction effects: class interval by disease (non-uniform DIF) |       |       |         |         |
|-------------------------|----------------------|-------------------------|---------|--|-------|-------|---------|---------|
|                         | MS                   | F                       | p-value | MS   | F     | DF    | p-value |         |
| Social impact           | 0.475                | 0.661                   | 2       | 0.517  | 1.013 | 1.408 | 18      | 0.119   |
| Impact on<br>appearance | 2.677                | 3.467                   | 2       | 0.032  | 0.421 | 0.545 | 18      | 0.937   |
| Psychological<br>impact | 3.454                | 4.903                   | 2       | 0.008  | 0.573 | 0.814 | 18      | 0.685   |
| Treatment<br>Concerns   | 9.481                | 12.013                  | 2       | <0.001   | 0.629 | 0.797 | 18      | 0.705   |
| Expected                |                      |                         |         | >0.0125  |       |       |         | >0.0125 |

## Supplementary Figure S1: Item characteristic curves for DIF analysis in the disease groups.



