

## Data Collection Worksheet

**Please Note:** The Data Collection Worksheet (DCW) is a tool to aid integration of a PhenX protocol into a study. The PhenX DCW is not designed to be a data collection instrument. Investigators will need to decide the best way to collect data for the PhenX protocol in their study. Variables captured in the DCW, along with variable names and unique PhenX variable identifiers, are included in the PhenX Data Dictionary (DD) files.

Please tick the box which represents your answer.

All questions refer to **last week** .

1. How would you describe the overall level of fatigue/tiredness you have experienced?

|      |   |   |   |   |   |   |   |   |   |   |    |             |
|------|---|---|---|---|---|---|---|---|---|---|----|-------------|
| None | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Very severe |
|------|---|---|---|---|---|---|---|---|---|---|----|-------------|

2. How would you describe the overall level of AS neck, back or hip pain you have had?

|      |   |   |   |   |   |   |   |   |   |   |    |             |
|------|---|---|---|---|---|---|---|---|---|---|----|-------------|
| None | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Very severe |
|------|---|---|---|---|---|---|---|---|---|---|----|-------------|

3. How would you describe the overall level of pain/swelling in joints **other than** neck, back or hips you have had?

|      |   |   |   |   |   |   |   |   |   |   |    |             |
|------|---|---|---|---|---|---|---|---|---|---|----|-------------|
| None | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Very severe |
|------|---|---|---|---|---|---|---|---|---|---|----|-------------|

4. How would you describe the overall level of discomfort you have had from any areas tender to touch or pressure?

|      |   |   |   |   |   |   |   |   |   |   |    |             |
|------|---|---|---|---|---|---|---|---|---|---|----|-------------|
| None | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Very severe |
|------|---|---|---|---|---|---|---|---|---|---|----|-------------|

5. How would you describe the overall level of morning stiffness you have had from the time you wake up?

|      |   |   |   |   |   |   |   |   |   |   |    |             |
|------|---|---|---|---|---|---|---|---|---|---|----|-------------|
| None | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Very severe |
|------|---|---|---|---|---|---|---|---|---|---|----|-------------|

6. How long does your morning stiffness last from the time you wake up?

|       |   |   |   |   |      |   |   |   |   |               |
|-------|---|---|---|---|------|---|---|---|---|---------------|
| 0     | 1 | 2 | 3 | 4 | 5    | 6 | 7 | 8 | 9 | 10            |
| 0 hrs |   |   |   |   | 1 hr |   |   |   |   | 2 or more hrs |

### Recommendations to score:

The scores for questions 5 and 6 (severity and duration of morning stiffness) are averaged; the result is then averaged with the remaining 4 question scores to give a final score out of 10.

### Score Interpretation

Ranges from 0 (no disease activity) to 10 (maximal disease activity).

### Cut-off points

Define: A cut off of  $\geq 4$  is used to define active disease. Reference percentile charts have been published. A 50% or 2 units (0-10) improvement in BASDAI with an intervention has been defined as a response to that intervention.

Protocol source: <https://www.phenxtoolkit.org/protocols/view/171101>