



## 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.

### 1a. Do you still have the heavy limbs?

- Yes, I still have this symptom
- Yes, I still have the symptom but it is less severe
- Yes, I still have the symptom but it comes and goes
- No, the symptom has cleared

### 1b. Does/did the heavy limbs affect your ability to do your normal activities?

- I have/had the symptom but I can/could still do normal activities.
- The symptom really bothers/bothered me. It is/was hard to do normal activities.
- The symptom is/was very bad. I am/was not able to do activities that I usually do.
- Refuse to answer

### 1c. When did the heavy limbs clear?

- Less than 3 months after symptom started
- Between 3 to 6 months after symptom started
- Between 6 to 9 months after symptom started
- Greater than 9 months after symptom started
- Don't know
- Refuse to answer

### 2a. Do you still have the rapid heart rate?

- Yes, I still have this symptom

- Yes, I still have the symptom but it is less severe
- Yes, I still have the symptom but it comes and goes
- No, the symptom has cleared

2b. Does/did the rapid heart rate affect your ability to do your normal activities?

- I have/had the symptom but I can/could still do normal activities.
- The symptom really bothers/bothered me. It is/was hard to do normal activities.
- The symptom is/was very bad. I am/was not able to do activities that I usually do.
- Refuse to answer

2c. When did the rapid heart rate clear?

- Less than 3 months after symptom started
- Between 3 to 6 months after symptom started
- Between 6 to 9 months after symptom started
- Greater than 9 months after symptom started
- Don't know
- Refuse to answer

3a. Do you still have the slow heart rate?

- Yes, I still have this symptom
- Yes, I still have the symptom but it is less severe
- Yes, I still have the symptom but it comes and goes
- No, the symptom has cleared

3b. Does/did the slow heart rate affect your ability to do your normal activities?

- I have/had the symptom but I can/could still do normal activities.
- The symptom really bothers/bothered me. It is/was hard to do normal activities.
- The symptom is/was very bad. I am/was not able to do activities that I usually do.
- Refuse to answer

3c. When did the slow heart rate clear?

- Less than 3 months after symptom started
- Between 3 to 6 months after symptom started
- Between 6 to 9 months after symptom started
- Greater than 9 months after symptom started
- Don't know
- Refuse to answer

4a. Do you still have chills/repeated shaking with chills?

- Yes, I still have this symptom
- Yes, I still have the symptom but it is less severe
- Yes, I still have the symptom but it comes and goes
- No, the symptom has cleared

4b. Does/did the chills/repeated shaking with chills affect your ability to do your normal activities?

- I have/had the symptom but I can/could still do normal activities.
- The symptom really bothers/bothered me. It is/was hard to do normal activities.
- The symptom is/was very bad. I am/was not able to do activities that I usually do.
- Refuse to answer

4c. When did the chills/repeated shaking with chills clear?

- Less than 3 months after symptom started
- Between 3 to 6 months after symptom started
- Between 6 to 9 months after symptom started
- Greater than 9 months after symptom started
- Don't know
- Refuse to answer

5a. Do you still always feel hot or cold (temperature dysregulation)?

- Yes, I still have this symptom
- Yes, I still have the symptom but it is less severe

Yes, I still have the symptom but it comes and goes

No, the symptom has cleared

5b. Does/did the always feeling hot or cold (temperature dysregulation) affect your ability to do your normal activities?

I have/had the symptom but I can/could still do normal activities.

The symptom really bothers/bothered me. It is/was hard to do normal activities.

The symptom is/was very bad. I am/was not able to do activities that I usually do.

Refuse to answer

5c. When did the always feeling hot or cold (temperature dysregulation) clear?

Less than 3 months after symptom started

Between 3 to 6 months after symptom started

Between 6 to 9 months after symptom started

Greater than 9 months after symptom started

Don't know

Refuse to answer

6a. Do you still feel dizzy or lightheaded when standing up after sitting (orthostatic hypotension)?

Yes, I still have this symptom

Yes, I still have the symptom but it is less severe

Yes, I still have the symptom but it comes and goes

No, the symptom has cleared

6b. Does/did the feeling dizzy or lightheaded when standing up after sitting (orthostatic hypotension) affect your ability to do your normal activities?

I have/had the symptom but I can/could still do normal activities.

The symptom really bothers/bothered me. It is/was hard to do normal activities.

The symptom is/was very bad. I am/was not able to do activities that I usually do.

Refuse to answer

6c. When did the feeling dizzy or lightheaded when standing up after sitting (orthostatic hypotension) clear?

- Less than 3 months after symptom started
- Between 3 to 6 months after symptom started
- Between 6 to 9 months after symptom started
- Greater than 9 months after symptom started
- Don't know
- Refuse to answer

Protocol source: <https://www.phenxtoolkit.org/protocols/view/992009>