



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 muscle weakness?

- 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 muscle weakness 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 muscle weakness 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 muscle aches?

- 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 muscle aches 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 muscle aches 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 joint aches?

- 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 joint aches 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 joint aches 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/992018>