



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.

1. Marital status of primary caregiver

- Married
- Widowed
- Separated
- Divorced
- Never married
- Living with partner
- Refused to answer
- Unknown

2. Relationship of primary caregiver to patient

- Mother
- Father
- Niece or nephew
- Aunt or uncle
- First cousin
- Second cousin
- Unknown cousin
- Grandparent

- Great grandparent
- Great great grandparent
- Great aunt or uncle
- Great great aunt or great great uncle
- Foster parent
- Other Specify _____

Protocol source: <https://www.phenxtoolkit.org/protocols/view/840101>