



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.

These questions ask about your own health care. Do not include care you got when you stayed overnight in a hospital. Do not include the times you went for dental care visits.

1. In the last 12 months, did a doctor or other health provider give you instructions about what to do about a specific illness or health condition?

Yes → **Go to 2**
 No → **If No, go to 4**

2. In the last 12 months, how often were these instructions easy to understand?

Never
 Sometimes
 Usually
 Always

3. In the last 12 months, how often did doctors or other health providers ask you to describe how you were going to follow these instructions?

Never
 Sometimes
 Usually
 Always

4. In the last 12 months, did you have to fill out or sign any forms at a doctor's or other health provider's office?

Yes → **Go to 5**
 No → **If No, go to 6**

5. In the last 12 months, how often were you offered help in filling out a form at the doctor's or other health provider's office?

Never

- Sometimes
- Usually
- Always

6. In the last 12 months, how often did doctors or other health professionals explain things in a way that was easy to understand?

- Never
- Sometimes
- Usually
- Always

7. In the last 12 months, how often did doctors or other health professionals listen carefully to you?

- Never
- Sometimes
- Usually
- Always

8. In the last 12 months, how often did doctors or other health professionals show respect for what you had to say?

- Never
- Sometimes
- Usually
- Always

9. In the last 12 months, how often did doctors or other health professionals spend enough time with you?

- Never
- Sometimes
- Usually
- Always

When you answer the next questions, do not include dental visits or care you got when you stayed overnight in a hospital.

10. Specialists are doctors like surgeons, heart doctors, allergy doctors, skin doctors, and other doctors who specialize in one area of health care. In the last 12 months, did you make any appointments to see a specialist?

- Yes → **Go to 11**
- No → **If No, please go to the “Date completed” boxes below**

11. In the last 12 months, how often did you get an appointment to see a

specialist as soon as you needed?

- Never
- Sometimes
- Usually
- Always

Date Completed: __ __ / __ __ / __ __ __ __ (MM/DD/YYYY)

Who completed this form?

- Person named on front of this form
- Someone else, → **Go to next**

If Someone Else, what is person's relationship to the person named on the front of this form?

- Husband or wife
- Unmarried partner
- Son or daughter
- Other relative
- Not related

Protocol source: <https://www.phenxtoolkit.org/protocols/view/281101>