



## 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.

### Section 1. Changes to Your Work Schedule

1. At any time from when you were first diagnosed with cancer until now, were you working for pay at a job or business?

Yes

No →GO TO Question 38

These next questions ask about different ways cancer, its treatment, or the lasting effects of that treatment may have affected your work - that is, your hours, duties, or employment status.

As you answer these questions, please think about the entire time from when you were first diagnosed with cancer to now.

If you have had more than one type of cancer please think about your experiences across all of them. If that is not possible, please focus on the most severe, and if they were equally severe, please focus on the most recent.

2. At any time since your first cancer diagnosis, did you take extended paid time off from work, unpaid time off, or make a change in your hours, duties or employment status?

Yes→ GO TO Question 5

No

3. At any time since your first cancer diagnosis, did you ask for extended paid time off from work, unpaid time off, or a change in your hours, duties or employment status?

Yes

No→ GO TO Question 27

4. Did you ask for these work changes...

Because of your cancer, its treatment or its lasting effect →GO TO Question 27

Some other reason? →GO TO Question 27

5. Did you make these work changes...

Because of your cancer, its treatment or its lasting effects?

Some other reason? →GO TO Question 27

6. Did you ever take extended time off from work (vacation, sick time and/or disability leave)? By extended time off, we mean more than an occasional day off here and there.

Yes

No →GO TO Question 10

7. When did you take extended paid time off from work?

Mark x all that apply.

At the time of diagnosis

During treatment

Less than one year after treatment was finished

One year or more after treatment was finished

8. What do you estimate was the total amount of extended paid time off from work that you took?

Less than 2 months

2 months to less than 6 months

6 months to less than 1 year

1 year to 3 years

More than 3 years

9. Is your extended paid time off from work ongoing?

Yes

No

10. Did you ever take unpaid time off from work?

Yes

No →GO TO Question 14

11. When did you take unpaid time off from work?

Mark x all that apply.

At the time of diagnosis

During treatment

Less than one year after treatment was finished

One year or more after treatment was finished

12. What do you estimate was the total amount of unpaid time off from work that you took?

Less than 2 months

2 months to less than 6 months

6 months to less than 1 year

1 year to 3 years

More than 3 years

13. Is your unpaid time off ongoing?

Yes

No

14. Did you ever change from working part-time to working full-time?

Yes

No→ GO TO Question 18

15. When did you change from working part-time to working full-time?

Mark x all that apply.

At the time of diagnosis

During treatment

Less than one year after treatment was finished

One year or more after treatment was finished

16. What do you estimate was the total amount of time you worked full-time?

Less than 2 months

2 months to less than 6 months

6 months to less than 1 year

1 year to 3 years

More than 3 years

17. Is this change ongoing?

Yes

No

18. Did you ever change from working full-time to working part-time?

Yes

No →GO TO Question 22

19. When did you change from working full-time to working part-time?

Mark X all that apply.

At the time of diagnosis

During treatment

Less than one year after treatment was finished

One year or more after treatment was finished

20. What do you estimate was the total amount of time you worked part-time?

Less than 2 months

2 months to less than 6 months

6 months to less than 1 year

1 year to 3 years

More than 3 years

21. Is this change ongoing?

Yes

No

22. Did you ever change from a set work schedule, where you start and end at the same time every day, to a flexible work schedule, where your start and end times vary from day-to-day?

Yes

No →GO TO Question 24

23. When did you change to a flexible work schedule?

Mark x all that apply.

At the time of diagnosis

During treatment

Less than one year after treatment was finished

One year or more after treatment was finished

24. Did you ever change to a less demanding job?

Yes

No →GO TO Question 27

25. When did you change to a less demanding job?

Mark x all that apply.

At the time of diagnosis

During treatment

Less than one year after treatment was finished

One year or more after treatment was finished

26. Is the change ongoing?

Yes

No

27. Did you make any other type of work arrangements because of your cancer, its

treatment, or the lasting effects of that treatment?

Yes

No →GO TO Question 28

If Yes, please describe:


28. Because of your cancer, its treatment, or the lasting effects of that treatment, did you ever decide not to pursue an advancement or promotion?

Yes

No

29. Because of your cancer, its treatment, or the lasting effects of that treatment, did you retire earlier than you had planned?

Yes →GO TO Section 2

No

30. Because of your cancer, its treatment, or the lasting effects of that treatment, did you delay retirement beyond when you had planned?

Yes

No

## Section 2. Other Aspects of Work

Please continue to think about all your work experiences from the time you were first diagnosed with cancer to now.

If you have had more than one type of cancer please think about your experiences across all of them. If that is not possible, please focus on the most severe, and if they were equally severe, please focus on the most recent.

31. Did you ever feel that your cancer, its treatment, or the lasting affects of that treatment interfered with your ability to perform any physical tasks required by

your job?

Yes

No

I was never required to perform physical tasks as part of my job

32. Did you ever feel that your cancer, its treatment, or the lasting effects of that treatment interfered with your ability to perform any mental tasks required by your job?

Yes

No

33. Did you ever feel that, because of your cancer, its treatment, or the lasting effects of that treatment, you were less productive at work?

Yes

No

34. Did you ever worry that, because of the effects of cancer on your health, you might be forced to retire or quit work before you are ready?

Yes

No

35. Did you ever stay at a job in part because you were concerned about losing your health insurance?

Yes

No →GO TO Question 37

36. Were you concerned about losing your health insurance because of your cancer?

Yes

No

37. Thinking about your work life or career, what effect has your experience with cancer, its treatment, or the lasting effects of that treatment had on it?

Mostly positive effect

Mostly negative effect

Equally positive and negative effect

Neither positive nor negative effect

38. Did your spouse or significant other ever stay at a job in part because he/she was concerned about losing health insurance for the family?

Yes

No

Does not apply

Protocol source: <https://www.phenxtoolkit.org/protocols/view/320101>