



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.

BURDEN ASSESSMENT SCALE

I am going to read a list of things which other people have found to happen to them because of their relative's illness. Would you tell me to what extent you have had any of the following experiences in the past six months.

 1 2 3 4 9

Not at all

A little

Some

A lot

NA

Because of (name's) illness, to what extent have you:

_____ 1. Had financial problems

 1 2 3 4 9

Not at all

A little

Some

A lot

NA

_____ 2. Missed days at work (or school)

 1 2 3 4 9

Not at all

A little

Some

A lot

NA

_____ 3. Found it difficult to concentrate on your own activities

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>9</u>
Not at all	A little	Some	A lot	NA

_____ 4. Had to change your personal plans like taking a new job, or going on vacation

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>9</u>
Not at all	A little	Some	A lot	NA

_____ 5. Cut down on leisure time

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>9</u>
Not at all	A little	Some	A lot	NA

_____ 6. Found the household routine was upset

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>9</u>
Not at all	A little	Some	A lot	NA

_____ 7. Had less time to spend with friends

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>9</u>
Not at all	A little	Some	A lot	NA

_____ 8. Neglected other family members' needs

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>9</u>
Not at all	A little	Some	A lot	NA

_____ 9. Experienced family frictions and arguments

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>9</u>
Not at all	A little	Some	A lot	NA

_____ 10. Experienced frictions with neighbors, friends, or relatives outside the home

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>9</u>
Not at all	A little	Some	A lot	NA

_____ 11. Became embarrassed because of (name's) behavior

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>9</u>
Not at all	A little	Some	A lot	NA

_____ 12. Felt guilty because you were not doing enough to help

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>9</u>
Not at all	A little	Some	A lot	NA

_____ 13. Felt guilty because you felt responsible for causing (name's) problem

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>9</u>
Not at all	A little	Some	A lot	NA

_____ 14. Resented (name) because s/he made too many demands on you

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>9</u>
Not at all	A little	Some	A lot	NA

_____ 15. Felt trapped by your caregiving role

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>9</u>
Not at all	A little	Some	A lot	NA

_____ 16. Were upset about how much (name) had changed from his or her former self

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>9</u>
Not at all	A little	Some	A lot	NA

_____ 17. Worried about how your behavior with (name) might make the illness worse

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>9</u>
Not at all	A little	Some	A lot	NA

_____ 18. Worried about what the future holds for (name)

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>9</u>
Not at all	A little	Some	A lot	NA

_____ 19. Found the stigma of the illness upsetting

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>9</u>
Not at all	A little	Some	A lot	NA

Scoring: Ratings from each item are added together to give a total score, with higher scores indicating greater levels of caregiver burden.

Protocol source: <https://www.phenxtoolkit.org/protocols/view/662201>