

Data Collection Worksheet

Please Note: The Data Collection Worksheet (DCW) is a tool to aid investigators to integrate the collection of PhenX measures in your study. The PhenX measures that you selected and added to your Cart are presented in the DCW in alphabetical order. The DCW includes worksheets for data collection. Variables derived from the collected data are shown in the Data Dictionary (DD) with variable names and unique PhenX variable identifiers. The collection of DCWs produced by the Toolkit is not designed as a data collection instrument. Each investigator will decide how to integrate PhenX measures into data collection for their study.

SECTION A: [Major Depressive Episode]

A1a. Have you ever had a time in your life when you felt sad, blue, or depressed for two weeks or more in a row?

1 Yes

2 No

-1 Refused

-2 Not Asked

A1b. Have you ever had a time in your life lasting two weeks or more when you lost interest in most things like hobbies, work, or activities that usually give you pleasure?

1 Yes

2 No

-1 Refused

-2 Not Asked

IF NO or skip to A1a AND A1b, skip to section B. If YES to either of the two, continue to A1c.

Please think of the two-week period in your life when your feelings of depression or loss of interest were worst:

A1c. How much of the day did these feeling usually last?

- 1 All day long
- 2 Most of the day
- 3 About half of the day [skip to B1]
- 4 Less than half of the day [skip to B1]
- 1 Refused
- 2 Not Asked

A1d. Did you feel this way:

- 1 Every day
- 2 Almost every day
- 3 Less often [skip to B1]
- 1 Refused
- 2 Not Asked

A2. Did you feel more tired out or low on energy than is usual for you?

- 1 Yes
- 2 No
- 1 Refused
- 2 Not Asked

A3. Did you gain or lose weight without trying, or did you stay about the same weight?

- 1 Gained [go to A3aa]
- 2 Lost [go to A3ab]
- 3 Both gained and lost weight [go to A3ac]
- 4 Stayed about the same or on a diet [go to A4]
- 1 Refused
- 2 Not Asked

A3aa. About how much weight did you gain?

_____ pounds

A3ab. About how much weight did you lose?

_____ pounds

A3ac. About how much weight did you gain and lose?

Gained _____ pounds

Lost _____ pounds

A4. Did you have more trouble falling asleep than you usually do?

1 Yes [go to A5]

2 No

-1 Refused

-2 Not Asked

[If skip, go to A5]

A4a. How often did that happen?

1 Every night

2 Nearly every night

3 Less often

-1 Refused

-2 Not Asked

A5. Did you have a lot more trouble concentrating than usual?

1 Yes

2 No

-1 Refused

-2 Not Asked

A6. People sometimes feel down on themselves, no good, or worthless. Did you feel this way?

1 Yes

2 No

-1 Refused

-2 Not Asked

A7. Did you think a lot about death - either your own, someone else's, or death in general?

1 Yes

2 No

-1 Refused

-2 Not Asked

Please again think of the two-week period in your life when your feelings of depression or loss of interest were worst:

A8. About how many weeks altogether did you feel this way? Count the weeks before, during and after the worst two weeks. The total period of depression/loss of interest was:

_____ weeks

A8a. How many periods like this did you have in your life, lasting two or more weeks?

_____ periods

A8b. About how old were you the FIRST time you had a period of two weeks like this? (Whether or not you received any help for it.)

_____ years of age when you first felt this way

A8c. About how old were you the LAST time you had a period of two weeks like this? (Whether or not you received any help for it.)

_____ years of age when the most recent episode happened

A8d. Did you ever tell a professional about these problems (medical doctor, psychologist, social worker, counselor, nurse, clergy, or other helping professional)?

1 Yes

2 No

-1 Refused

-2 Not Asked

A8e. Did you take medication or use drugs or alcohol more than once for these problems?

1 Yes

2 No

-1 Refused

-2 Not Asked

A8f. How much did these problems interfere with your life or activities:

1 A lot

2 Some

3 A little

- 4 Not at all
- 1 Refused
- 2 Not Asked

SECTION B: [Generalized Anxiety Disorder]

B1. Have you ever had a period lasting one month or longer when most of the time you felt worried, tense, or anxious?

- 1 Yes [go to B2]
- 2 No
- 1 Refused
- 2 Not Asked

B1a. People differ a lot in how much they worry about things. Did you ever have a time when you worried a lot more than most people would in your situation?

- 1 Yes
 - 2 No [go to C1]
 - 1 Refused
 - 2 Not Asked
- [if B1a=1]

B2. What is the longest period of time that this kind of worrying has ever continued?

_____ years and _____ months

or _____ all of my life/as long as I can remember

[if B2 is less than 6 months, go to C]

Please think of the period in your life when you have felt worried, tense, anxious, or more worried than most people would in your situation. This could be in the past, or it could be continuing now.

B4. During that period, was your worry stronger than in other people?

1 Yes

2 No

-1 Refused

-2 Not Asked

B5. Did you worry most days?

1 Yes

2 No

-1 Refused

-2 Not Asked

B6. Did you usually worry about one particular thing, such as your job security or the failing health of a loved one, or more than one thing?

1 One thing

2 More than one thing

-1 Refused

-2 Not Asked

B7. Did you find it difficult to stop worrying?

1 Yes

2 No

-1 Refused

-2 Not Asked

B8. Did you ever have different worries on your mind at the same time?

1 Yes

2 No

-1 Refused

-2 Not Asked

B9. How often was your worry so strong that you couldn't put it out of your mind no matter how hard you tried?

1 Often

2 Sometimes

3 Rarely

4 Never

-1 Refused

-2 Not Asked

B10. How often did you find it difficult to control your worry?

1 Often

2 Sometimes

3 Rarely

4 Never

-1 Refused

-2 Not Asked

B12. When you were worried or anxious, were you also:

B12a. Restless?	q 1 Yes q 2 No
B12b. Keyed up or on edge?	q 1 Yes q 2 No

B12c. Easily tired?	q 1 Yes q 2 No
B12d. Having difficulty keeping your mind on what you were doing?	q 1 Yes q 2 No
B12e More irritable than usual?	q 1 Yes q 2 No
B12f. Having tense, sore, or aching muscles?	q 1 Yes q 2 No
B12g. Often having trouble falling or staying asleep?	q 1 Yes q 2 No

B14. Did you ever tell a professional about these problems (medical doctor, psychologist, social worker, counselor, nurse, clergy, or other helping professional)?

1 Yes

2 No

-1 Refused

-2 Not Asked

B15. Did you take medication or use drugs or alcohol more than once for the worry or the problems it was causing?

1 Yes

2 No

-1 Refused

-2 Not Asked

B16. How much did the worry or anxiety interfere with your life or activities?

1 A lot

2 Some

3 A little

4 [] Not at all

-1 [] Refused

-2 [] Not Asked

SECTION C: [Specific Phobia]

C1. The next questions are about things that make some people so afraid that they avoid them, even when there is no real danger.

Do you have an unreasonably strong fear or avoid any of the following things:

C1a. Heights, storms, thunder, lightning, or being in still water, like a swimming pool or lakes?	q 1 Yes q 2 No
C1b. Being in a closed space like a cave, tunnel, elevator, or airplane?	q 1 Yes q 2 No
C1c. Snakes, birds, rats, bugs, or other animals?	q 1 Yes q 2 No
C1d. Seeing blood, getting a shot or injection, seeing a dentist, or going to a hospital?	q 1 Yes q 2 No

[If 0 Yes responses to C1 series, go to D1]

[repeat the following statement for the rest of Section C]

C2. Please think of the situations that you fear such as: [Insert situations respondent feared from Section C1]. How often do you get upset when you are in that situation?

1 [] Every time

2 [] Most of the time

3 [] Some of the time [go to D1]

4 [] Only one or two times ever [go to D1]

5 [] Never [go to D1]

-1 [] Refused

-2 [] Not Asked

C4. Please think of the situations that you fear such as: [Insert situations respondent feared from Section C1] . How long have you had any of these fears?

1 [] Less than 1 year (_____# of months)

2 [] Between 1 and 5 years

3 [] More than 5 years

C5. Please think of the situations that you fear such as: [Insert situations respondent feared from Section C1] . How much have any of these fears ever interfered with your life or activities?

1 [] A lot

2 [] Some

3 [] A little

4 [] Not at all

-1 [] Refused

-2 [] Not Asked

C6. Please think of the situations that you fear such as: [Insert situations respondent feared from Section C1] . Have you ever been very upset with yourself for having any of these fears?

1 [] Yes

2 [] No

-1 [] Refused

-2 [] Not Asked

C7. Please think of the situations that you fear such as: [Insert situations respondent feared from Section C1] . Is your fear unreasonable - that is, much stronger than it should be?

1 [] Yes

2 [] No

-1 [] Refused

-2 [] Not Asked

C8. Please think of the situations that you fear such as: [Insert situations respondent feared from Section C1] . Is your fear much stronger than in other people?

1 [] Yes

2 [] No

-1 [] Refused

-2 [] Not Asked

SECTION D: [Social Phobia]

D1. Here's another list of situations that can cause unreasonably strong fears. They involve doing things in front of other people or being the center of attention. Do you have an unreasonably strong fear or avoid any of the following situations:

D1a. Giving a speech or speaking in public?	q 1 Yes q 2 No
D1b. Eating or drinking where someone could watch you?	q 1 Yes q 2 No
D1c. Talking to people because you might have nothing to say or might sound foolish?	q 1 Yes q 2 No
D1d. Writing while someone watches?	q 1 Yes q 2 No
D1e. Taking part or speaking in a meeting or class?	q 1 Yes q 2 No
D1f. Going to a party or other social outing?	q 1 Yes q 2 No

[if 0 Yes responses to D1 series, go to E1]

[repeat the following statement for the rest of Section D]

Please think only of the situation(s) that cause you unreasonably strong fears such as:

D2. How often do you get very upset when you are in this situation?

- 1 Every time
- 2 Most of the time
- 3 Some of the time [go to E1]
- 4 Only one or two times ever [go to E1]
- 5 Never [go to E1]
- 1 Refused
- 2 Not Asked

D3. How long have you had any of these fears?

- 1 Less than 1 year (_____# of months)
- 2 Between 1 and 5 years
- 3 More than 5 years
- 1 Refused
- 2 Not Asked

D4. How much have any of these fears ever interfered with your life or activities?

- 1 A lot
- 2 Some
- 3 A little
- 4 Not at all
- 1 Refused
- 2 Not Asked

D5. Have you ever been very upset with yourself for having any of these fears?

- 1 Yes

2 [] No

-1 [] Refused

-2 [] Not Asked

D6. Is your fear unreasonable - that is, much stronger than it should be?

1 [] Yes

2 [] No

-1 [] Refused

-2 [] Not Asked

D7. Is your fear much stronger than in other people?

1 [] Yes

2 [] No

-1 [] Refused

-2 [] Not Asked

SECTION E: [Agoraphobia]

E1. Here's a final list of situations that can cause unreasonably strong fears. Do you have an unreasonably strong fear for or avoid any of the following:

E1a. Being in a crowd or standing in line?	q 1 Yes q 2 No
E1b. Being away from home alone?	q 1 Yes q 2 No
E1c. Traveling alone?	q 1 Yes q 2 No
E1d. Traveling in a bus, train, or car?	q 1 Yes q 2 No
E1e. Being in a public place	q 1 Yes q 2 No

like a department store?	
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[if 0 Yes responses to E1 series, go to F]

[repeat the following statement between E2-E8]

Please think only of the situation(s) that cause you to have unreasonably strong fears, such as:

E2. How often do you get very upset in the situation?

- 1 Every time
- 2 Most of the time
- 3 Some of the time [go to F1]
- 4 Only one or two times ever [go to F1]
- 5 Never [go to F1]
- 1 Refused
- 2 Not Asked

E4. How long have you had any of these fears?

- 1 Less than 1 year (_____# of months)
- 2 Between 1 and 5 years
- 3 More than 5 years
- 1 Refused
- 2 Not Asked

E5. Were you ever afraid that you might faint, lose control, or embarrass yourself in other ways?

- 1 Yes
- 2 No
- 1 Refused
- 2 Not Asked

E6. Do you worry that you might be trapped without any way to escape?

1 Yes

2 No

-1 Refused

-2 Not Asked

E7. Do you worry that help might not be available if you needed it?

1 Yes

2 No

-1 Refused

-2 Not Asked

E8. How much did any of these fears ever interfere with your life or activities?

1 A lot

2 Some

3 A little

4 Not at all

-1 Refused

-2 Not Asked

SECTION F: [Panic Attack]

F1. Did you ever have a spell or an attack when all of a sudden you felt frightened, anxious, or very uneasy?

1 Yes

2 No [go to G1]

-1 Refused

-2 [] Not Asked

F1a. Did any of these attacks occur when you were in a life-threatening situation?

1 [] Yes

2 [] No [go to F2]

-1 [] Refused

-2 [] Not Asked

[if skip, go to F1b]

F1b. Did any of these attacks occur when you were not in a life-threatening situation?

1 [] Yes

2 [] No [go to G1]

-1 [] Refused

-2 [] Not Asked

F2. About how many attacks have you had in your life?

Please enter the number of attacks you have had in your life in the box below.

-1 [] Refused

-2 [] Not Asked

F3. How long ago did you have the most recent attack?

_____ months ago (enter 0 if you had one in the past month)

-1 [] Refused

-2 [] Not Asked

F4. Did some of your attacks happen in a situation when you were not in danger or not the center of attention?

1 Yes

2 No [go to G1]

-1 Refused

-2 Not Asked

F5. We already asked about specific situations that cause unreasonably strong fears (heights, elevators, snakes, etc.).

When you have sudden anxiety attacks, do they usually occur in specific situations that cause you unreasonably strong fear?

1 Yes

2 No [go to F6]

-1 Refused

-2 Not Asked

F5a. Did you ever have an attack when you were not in a situation that usually causes you to have unreasonably strong fears?

1 Yes

2 No [go to G1]

-1 Refused

-2 Not Asked

F6. When you have attacks:

F6a. Does your heart pound or race?	q 1 Yes q 2 No
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F6b. Do you have tightness, pain, or discomfort in your chest or stomach?	q 1 Yes q 2 No
F6c. Do you sweat?	q 1 Yes q 2 No
F6d. Do you tremble or shake?	q 1 Yes q 2 No
F6e. Do you have hot flashes or chills?	q 1 Yes q 2 No
F6f. Do you, or things around you, seem unreal?	q 1 Yes q 2 No

SECTION I: [Obsessive Compulsive Disorder]

I1. Have you ever been bothered by having certain unpleasant thoughts of your own that kept entering your mind against your wishes? An example would be if you kept having the idea that your hands are dirty or have germs on them.

1 Yes

2 No

-1 Refused

-2 Not Asked

I2. Another example of an unpleasant thought would if you kept having the idea that you might harm someone, even though you really didn't want to. Or you might have had thoughts you were ashamed of, but couldn't keep out of your mind. Have you ever had any unpleasant and persistent thoughts like that?

1 Yes

2 No

-1 Refused

-2 Not Asked

[If either I1 or I2 coded yes: continue. All others go to I8]

[repeat the following statement from I3 to I6]

Please think about the time in your life when some of these unpleasant thoughts were bothering you the most.

I3. Please think about the time in your life when unpleasant thoughts were bothering you the most. [An example of an unpleasant thought would be if you kept having the idea that you might harm someone, even though you really didn't want to] . Did some of these thoughts seem to you to be unreasonable?

1 Yes

2 No

-1 Refused

-2 Not Asked

I4. Please think about the time in your life when unpleasant thoughts were bothering you the most. [An example of an unpleasant thought would be if you kept having the idea that you might harm someone, even though you really didn't want to] . Did these thoughts keep coming back again and again into your mind no matter how hard you tried to resist, ignore, or get rid of them?

1 Yes

2 No

-1 Refused

-2 Not Asked

I5. Please think about the time in your life when unpleasant thoughts were bothering you the most. [An example of an unpleasant thought would be if you kept having the idea that you might harm someone, even though you really didn't want to] .Did you ever tell a doctor about these thoughts?

1 Yes

2 No

-1 Refused

-2 Not Asked

16. Please think about the time in your life when unpleasant thoughts were bothering you the most. [An example of an unpleasant thought would be if you kept having the idea that you might harm someone, even though you really didn't want to] . Did thinking about these ideas interfere with your life or work, or cause you difficulty with your relatives or friends, or upset you a great deal?

1 Yes

2 No

-1 Refused

-2 Not Asked

17. Some people have the unpleasant feeling that they have to do something over and over again even though they know it is foolish, but they can't resist doing it - things like washing their hands again and again or going back several times to be sure they've locked a door or turned off the stove. Have you ever had to do something like that over and over?

1 Yes

2 No

-1 Refused

-2 Not Asked

18. Was there a time when you felt you had to do something in a certain order, like getting dressed perhaps, and had to start all over again if you did it in the wrong order?

1 Yes

2 No

-1 Refused

-2 Not Asked

19. Has there been a period of several weeks when you felt you had to count something, like the squares in a tile floor, and couldn't resist doing it even when you tried to?

1 Yes

2 No

-1 Refused

-2 [] Not Asked

I10. Did you have a period when you had to say certain words over and over, either aloud or to yourself?

1 [] Yes

2 [] No

-1 [] Refused

-2 [] Not Asked

[any of I7 through I10 coded yes, go to I13. all others go to M1]

[repeat the following statement from I13 to I15]

Please think about the time in your life when having to do these things was bothering you the most (doing or counting or checking something over and over, or in the same order).

I13. Please think about the time in your life when having to do these things was bothering you the most (doing or counting or checking something over and over, or in the same order). Did you think that these actions were unnecessary or that you overdid it?

1 [] Yes

2 [] No

-1 [] Refused

-2 [] Not Asked

I14. Please think about the time in your life when having to do these things was bothering you the most (doing or counting or checking something over and over, or in the same order). Did you tell a doctor about having to do these things?

1 [] Yes

2 [] No

-1 [] Refused

-2 [] Not Asked

115. Please think about the time in your life when having to do these things was bothering you the most (doing or counting or checking something over and over, or in the same order). Did having to do these things interfere with your life or work, or cause you difficulty with your relatives or friends, or upset you a great deal?

1 [] Yes

2 [] No

-1 [] Refused

-2 [] Not Asked

Section M: [other miscellaneous]

Have you ever *received treatment for*, or *been diagnosed with*, any of the following conditions:

M1a. Schizophrenia or schizoaffective disorder	q 1 Yes	2 No	3 Not sure
M1b. Hearing voices others could not hear or believing things that others said were not true (such as that people were trying to harm you)	q 1 Yes	2 No	3 Not sure
M1c. Bipolar disorder (manic-depression) (q 1 Yes	2 No	3 Not sure

SECTION K: [selected personality questions]

On the following screens, you will be asked a series of questions that may or may not describe you. Please answer each question by indicating 'YES or 'NO'. There are no right or wrong answers, and no trick questions. Work quickly and do not think too long about the exact meaning of the questions. **[When developing your study questionnaire, mix the N and E items together and number them consecutively from 1-24]**

K1. Does your mood often go up and down? [N1]	1 Yes	2 No
K2. Do you ever feel 'just miserable' for no reason? [N5]	1 Yes	2 No
K3. Are you an irritable person? [N9]	1 Yes	2 No
K4. Are your feelings easily hurt? [N13]	1 Yes	2 No
K5. Do you often feel 'fed-up'? [N17]	1 Yes	2 No
K6. Would you call yourself a nervous person? [N21]	1 Yes	2 No
K7. Are you a worrier? [N25]	1 Yes	2 No
K8. Would you call yourself tense or 'highly-strung'? [N30]	1 Yes	2 No
K9. Do you worry too long after an embarrassing experience? [N34]	1 Yes	2 No
K10. Do you suffer from 'nerves'? [N38]	1 Yes	2 No
K11. Do you often feel lonely? [N42]	1 Yes	2 No
K12. Are you often troubled about feelings of guilt? [N46]	1 Yes	2 No
K13. Are you a talkative person? [E3]	1 Yes	2 No
K14. Are you rather lively? [E7]	1 Yes	2 No
K15. Do you enjoy meeting new people? [E11]	1 Yes	2 No
K16. Can you usually let yourself go and enjoy yourself at a lively party? [E15]	1 Yes	2 No
K17. Do you usually take the initiative in making new friends? [E19]	1 Yes	2 No
K18. Can you easily get some life into a rather dull party? [E23]	1 Yes	2 No

K19. Do you tend to keep in the background on social occasions? [E27]	1 Yes	2 No
K20. Do you like mixing with people? [E32]	1 Yes	2 No
K21. Do you like plenty of bustle and excitement around you? [E36]	1 Yes	2 No
K22. Are you mostly quiet when you are with other people? [E41]	1 Yes	2 No
K23. Do other people think of you as being very lively? [E44]	1 Yes	2 No
K24. Can you get a party going? [E48]	1 Yes	2 No
	-1 Refused	
	-2 Not Asked	

Protocol source: <https://www.phenxtoolkit.org/protocols/view/120101#Source>