



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.

Questions about how much chest trouble you have had over the past 3 months.

Please tick/check *one*:

Please tick in one box to show how you describe your current health.

Very good

Good

Fair

Poor

Very poor

PART 1

Questions about how much chest trouble you have had over the past 3 months.

1. Over the past 3 months, I have coughed:

Most days a week

Several days a week

A few days a month

Only with chest infections

Not at all

2. Over the past 3 months, I have brought up phlegm (sputum):

Most days a week

Several days a week

- A few days a month
- Only with chest infections
- Not at all

3. Over the past 3 months, I have had shortness of breath:

- Most days a week
- Several days a week
- A few days a month
- Only with chest infections
- Not at all

4. Over the past 3 months, I have had attacks of wheezing:

- Most days a week
- Several days a week
- A few days a month
- Only with chest infections
- Not at all

5. During the past 3 months, how many severe or very unpleasant attacks of chest trouble have you had?

- More than 3 attacks
- 3 attacks
- 2 attacks
- 1 attack
- No attacks

6. How long did the worst attack of chest trouble last? (Go to question 7 if you had no severe attacks)

- A week or more
- 3 or more days
- 1 or 2 days

Less than a day

7. Over the past 3 months, in an average week, how many good days (with little chest trouble) have you had?

No good days

1 or 2 good days

3 or 4 good days

Nearly every day is good

Every day is good

8. If you have a wheeze, is it worse in the morning?

No

Yes

PART 2

Section 1

Please tick/check *one*:

9. How would you describe your chest condition?

The most important problem I have

Causes me quite a lot of problems

Causes me a few problems

Causes no problems

Please tick/check *one*:

10. If you have ever had paid employment.

My chest trouble made me stop work altogether

My chest trouble interferes with my work or made me change my work

My chest trouble does not affect my work

Section 2

11. *Questions about what activities usually make you feel breathless these days.*

Please tick/check in **each box** that applies to you **these days**:

Sitting or lying still

True

False

Getting washed or dressed

True

False

Walking around the home

True

False

Walking outside on the level

True

False

Walking up a flight of stairs

True

False

Walking up hills

True

False

Playing sports or games

True

False

Section 3

Some more questions about your cough and breathlessness these days.

12. Please tick/check in **each box** that applies to you **these days**:

My cough hurts

True

False

My cough makes me tired

True

False

I am breathless when I talk

True

False

I am breathless when I bend over

True

False

My cough or breathing disturbs my sleep

True

False

I get exhausted easily

True

False

Section 4

13. Questions about other effects that your chest trouble may have on you these days.

Please tick/check in **each box** that applies to you **these days**:

My cough or breathing is embarrassing in public

True

False

My chest trouble is a nuisance to my family, friends, or neighbors

True

False

I get afraid or panic when I cannot get my breath

True

False

I feel that I am not in control of my chest problem

True

False

I do not expect my chest to get any better

True

False

I have become frail or an invalid because of my chest

True

False

Exercise is not safe for me

True

False

Everything seems too much of an effort

True

False

Section 5

14. Questions about your medication. If you are receiving no medication go straight to section 6.

Please tick/check in **each box** that applies to you **these days**:

My medication does not help me very much

True

False

I get embarrassed using my medication in public

True

False

I have unpleasant side effects from my medication

True

False

My medication interferes with my life a lot

True

False

Section 6

15. These are questions about how your activities might be affected by your breathing.

Please tick/check in **each box** that applies to you **because of your breathing**:

I take a long time to get washed or dressed

True

False

I cannot take a bath or shower, or I take a long time

True

False

I walk slower than other people, or I stop for rests

True

False

Jobs such as housework take a long time, or I have to stop for rests

True

False

If I walk up one flight of stairs, I have to go slowly or stop

True

False

If I hurry or walk fast, I have to stop or slow down

True

False

My breathing makes it difficult to do things such as walk up hills, carry things up stairs, light gardening such as weeding, dance, play bowls, or play golf

True

False

My breathing makes it difficult to do things such as carry heavy loads, dig the garden or shovel snow, jog or walk at 5 miles per hour, play tennis, or swim

True

False

My breathing makes it difficult to do things such as very heavy manual work, run, cycle, swim fast, or play competitive sports

True

False

Section 7

16. We would like to know how your chest usually affects your daily life.

Please tick/check in **each box** that applies to you ***because of your chest trouble***:

I cannot play sports or games

True

False

I cannot go out for entertainment or recreation

True

False

I cannot go out of the house to do the shopping

True

False

I cannot do housework

True

False

I cannot move far from my bed or chair

True

False

Here is a list of other activities that your chest trouble may prevent you doing. (You do not have to tick these; they are just to remind you of ways in which your breathlessness may affect you):

Going for walks or walking the dog

Doing things at home or in the garden

Sexual intercourse

Going out to church, pub, club, or place of entertainment

Going out in bad weather or into smoky rooms

Visiting family or friends or playing with children

Please write in any other important activities that your chest trouble may stop you doing:

.....

.....

.....

17. Now would you tick in the box (one only) which you think best describes how your chest affects you:

It does not stop me doing anything I would like to do

It stops me doing one or two things I would like to do

It stops me doing most of the things I would like to do

[] It stops me doing everything I would like to do

Scoring Algorithms:

Three component scores are calculated: **Symptoms, Activity, and Impacts**

One **total** score is also calculated.

Principle of calculation

Each questionnaire response has a unique empirically derived "weight." The lowest possible weight is zero and the highest is 100.

Each component of the questionnaire is scored separately in three steps:

- i. The weights for all items with a positive response are summed.
- ii. The weights for missed items are deducted from the maximum possible weight for each component. The weights for all missed items are also deducted from the maximum possible weight for the total score.
- iii. The score is calculated by dividing the summed weights by the adjusted maximum possible weight for that component and expressing the result as a percentage:

Score = 100 x	$\frac{\text{Summed weights from positive items in that component}}{\text{Sum of weights for all items in that component}}$
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The total score is calculated similarly:

Score = 100 x	$\frac{\text{Summed weights from positive items in the questionnaire}}{\text{Sum of weights for all items in the questionnaire}}$
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Sum of maximum possible weights for each component and total:

Symptoms	662.5
Activity	1,209.1
Impacts	2,117.8

Total	3,989.4
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(Note: These are the maximum possible weights that could be obtained for the worst possible state of the patient.)

Note that the questionnaire requests a single response to questions 1-7, 9-10, and 17. If multiple responses are given to one of these questions, then averaging the weights for the positive responses for that question are acceptable. We feel that this is a better approach than losing an entire data set and have used this technique in calculating the results used in our validation studies. (Clearly a better approach is to prevent such multiple responses from occurring, but it is difficult to prevent occasional accidents). This method is used in the Excel calculator.

Symptoms Component

This is calculated from the summed weights for the positive responses to questions 1-8.

Activity Component

This is calculated from the summed weights for the positive responses to questions 11 and 15.

Impacts Component

This is calculated from the summed weights for the positive responses to questions 9-10, 12-14, and 16-17.

Total Score

The total score is calculated by summing all positive responses in the questionnaire and expressing the result as a percentage of the total weight for the questionnaire (as shown on previous page).

Handling Missed Items

It is better not to miss items and any missing items are the fault of the experimenter, not the patient. We have examined the effect of missing items and recommend the following methods:

Symptoms

The Symptoms component will tolerate a maximum of 2 missed items. The weight for the missed item is subtracted from the total possible weight for the Symptoms component (662.5) and from the total weight (3,989.4).

Activity

The Activity component will tolerate a maximum of 4 missed items. The weight for the missed item is subtracted from the total possible weight for the Activity component (1,209.1) and from the total weight (3,989.4).

Impacts

The Impacts component will tolerate a maximum of 6 missed items. The weight for the missed item is subtracted from the total possible weight for the Impacts component (2,117.8) and from the total weight (3,989.4).

Protocol source: <https://www.phenxtoolkit.org/protocols/view/91301>