



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.

This questionnaire has three sections containing questions about: A) your experiences with diseases and medication use, B) your knowledge on pharmacogenetics, C) your attitude towards pharmacogenetics.

The participation in this survey is voluntary. If you do not want to answer a particular question, you are of course free to do so. Please write the answers to open questions in the space provided. If you need more space, please use the back of the paper and indicate the question number. For all other questions, please use the checkboxes. If you want to change your answer, please put a line through the checked answer and then choose the appropriate box. Always check only one answer except if stated otherwise.

Experiences

Below are some questions about your personal experiences with diseases and medication use.

1. Have you ever experienced a side effect of a medication?

Yes

No

No, but a family member has

I do not know

2. Have you ever stopped taking a medication because of the side effects of this medication?

Yes

No

I do not know

3. Have you ever stopped taking a medication because you felt that it did not work?

Yes

No

I do not know

4. Do you think that there could be differences between people in their body's response to medication due to differences in their DNA?

Yes

No

I do not know

Knowledge

These questions enable us to know about your understanding of pharmacogenetics. If you do not know or are not sure, you can also indicate this as the answer.

The DNA stores your hereditary characteristics.

5. Do you think that determining the differences in DNA that are associated with the effect of medication will help to reduce (future) side effects?

Yes

No

I do not know

6. Do you think that knowing the differences in DNA that are associated with the effect of medication will help improve (future) drug treatment?

Yes

No

I do not know

“Pharmacogenetics looks at the influence of your genetic traits on the effect of medication. It is possible that different people break down medication differently due to variations in their genetic traits.”

7. Before you received this questionnaire, have you ever heard of the term “pharmacogenetics”?

Yes

No

8. Before you received this questionnaire, did you know the meaning of “pharmacogenetics”?

Yes

No

9. Have you ever had a pharmacogenetic test? In a pharmacogenetic test, your hereditary traits related to effect of a medication will be examined.

Yes

No

No, but I have had another kind of DNA test

I do not know

10. Do you know someone who has had a pharmacogenetic test?

Yes

No

No, but I know someone who has had another type of DNA-test

Attitude

Below are several questions about your views and attitude towards pharmacogenetics.

11. Suppose that your DNA is associated with the effects of your medication. Would you allow your doctor to use the information about your DNA in your future treatment?

Yes

No

I don't know, I have never thought about this

I have been thinking about this, but do not know yet

12. Are you willing to have a DNA test before a certain medication is prescribed?

Yes

No

I do not know

13. Do you want your pharmacogenetic information to be used in your treatment with medicines?

Yes, during the whole treatment

Yes, but only during my (potential) pregnancy

No

No opinion, I don't know

14. Would you take part in future research related to pharmacogenetics?

Yes, go to question 16

No, go to question 15

I do not know, go to question 15

15. If not, or in doubt, what is the reason (multiple answers are correct)?

I do not allow my DNA/genetic information to be used in research

I do not understand the benefit of genetic testing

I am worried about the consequences

I am not interested in pharmacogenetic research

Otherwise, please describe: _____

16. Would you like to learn more about DNA tests for pharmacogenetics?

Yes

No

I don't know

17. Which method of getting information about DNA tests for pharmacogenetics do you prefer (multiple answers are correct)?

Internet

Information leaflet

Advice from your pharmacist

Advice from your GP

Otherwise, please describe: _____

Protocol source: <https://www.phenxtoolkit.org/protocols/view/310301>