PhenX Toolkit

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.

1. Knowing about inherited risk (passed down within a family) can affect choices about cancer treatments (for example, medications or surgery).

[ ] Agree

[ ] Disagree

[ ] Don't know

2. People with an inherited risk for cancer (and their at-risk relatives) are more likely to develop more than one type of cancer.

[ ] Agree

[ ] Disagree

[ ] Don't know

3. A person with inherited risk for cancer will definitely get cancer one day.

[ ] Agree

[ ] Disagree

[ ] Don't know

4. The lifetime chance of getting cancer depends on which altered cancer gene is inherited.

[ ] Agree

[ ] Disagree

[ ] Don't know

5. People with an inherited risk for cancer may get cancer at a younger age than people with average risk.

[ ] Agree

[ ] Disagree

[ ] Don’t know

6. In the future, more information could become available that could alter the meaning of genetic test results.

[ ] Agree

[ ] Disagree

[ ] Don’t know

7. Female-specific cancer risk, such as ovarian cancer, can generally be passed on from either the father or mother.

[ ] Agree

[ ] Disagree

[ ] Don’t know

8. The blood relatives (for example, sister, father, or child) of a person with a mutation in a cancer risk gene might share the same gene mutation.

[ ] Agree

[ ] Disagree

[ ] Don’t know

9. A person with an inherited risk for cancer may have distant relatives (for example, cousins) who also have increased cancer risk.

[ ] Agree

[ ] Disagree

[ ] Don’t know

10. All children of a person with inherited cancer risk will also have inherited cancer risk.

[ ] Agree

[ ] Disagree

[ ] Don’t know

11. In most cases, the sisters and brothers of a person with inherited risk have a 50-50 (50%) chance of having inherited risk for cancer too.

[ ] Agree

[ ] Disagree

[ ] Don’t know

12. All of the gene mutations that could increase risk for cancer have been discovered.

[ ] Agree

[ ] Disagree

[ ] Don’t know

13. If a person does not have a mutation found on genetic testing (negative result), interpreting results will depend on whether someone in the family has a known gene mutation associated with cancer risk (positive result).

[ ] Agree

[ ] Disagree

[ ] Don’t know

14. Some gene mutations mean a larger increase in the risk for cancer while others mean a smaller increase in the risk for cancer.

[ ] Agree

[ ] Disagree

[ ] Don’t know

15. A Variant of Uncertain Significance (VUS) will not likely influence recommendations for screening or prevention.

[ ] Agree

[ ] Disagree

[ ] Don’t know

16. Multi-gene panel testing could find a mutation in a gene that is not clearly associated with the pattern of cancer in the family.

[ ] Agree

[ ] Disagree

[ ] Don’t know

Items 1, 2, 4, 5, 6, 7, 8, 9, 11, 13, 14,15, and 16, the correct answer is Agree.

Protocol source: https://www.phenxtoolkit.org/protocols/view/311601