



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. Has your tablet or smartphone...	Yes	No
a. helped you track progress on a health-related goal, such as quitting smoking, losing weight, or increasing physical activity?		
b. helped you make a decision about how to treat an illness or condition?		
c. helped you in discussions with your health care provider?		

2. Other than a tablet or smartphone, have you used an electronic device to monitor or track your health within the last 12 months? Examples include Fitbit, blood glucose meters, and blood pressure monitors.

Yes

No

3. Have you shared health information from either an electronic monitoring device or smartphone with a health professional within the last 12 months?

Yes

No

Not Applicable

4. Sometimes people use the Internet to connect with	Yes	No
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other people online through social networks like Facebook or Twitter. This is often called “social media”. In the past 12 months, have you used the Internet for any of the following reasons?		
a. To visit a social networking site, such as Facebook or LinkedIn		
b. To share health information on social networking sites, such as Facebook or Twitter		
c. To write in an online diary or blog (i.e., Web log)		
d. To participate in an online forum or support group for people with a similar health or medical issue		
e. To watch a health-related video on YouTube		

5. Have you sent a text message to or received a text message from a doctor or other health care professional within the last 12 months?

- Yes
- No
- Don't know

Next, we are going to ask you some questions about your medical records. Medical records are defined as medical history, such as laboratory test results, clinical notes, and current list of medications.

6. Do any of your doctors or other health care providers maintain your medical records in a computerized system?

- Yes
- No
- Don't know

7. How confident are you that safeguards (including the use of technology) are in place to protect your medical records from being seen by people who aren't

permitted to see them?

Very confident

Somewhat confident

Not confident

8. Have you ever kept information from your health care provider because you were concerned about the privacy or security of your medical record?

Yes

No

9. Have you ever been offered online access to your medical records by your health care provider or health insurer?

Yes -> GO TO 10.

No

Don't know

10. Who offered you online access to your medical records?

Mark all that apply.

Health care provider

Health insurer

Something else - Specify _____

11. How many times did you access your online medical record in the last 12 months?

0 -> GO TO 12.

1 to 2 times -> GO TO 13.

3 to 5 times -> GO TO 13.

6 to 9 times -> GO TO 13.

10 or more times -> GO TO 13.

12. Why have you not accessed your medical record online? Is it because...	Yes	No
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a. You prefer to speak to your health care provider directly?		
b. You do not have a way to access the website?		
c. You did not have a need to use your online medical record?		
d. You were concerned about the privacy or security of the website that had your medical records?		
e. You don't have an online medical record?		
f. Other (Specify) _____		

13. In the past 12 months, have you used your online medical record to...	Yes	No
a. Request refill of medications?		
b. Fill out forms or paperwork related to your health care?		
c. Request correction of inaccurate information?		
d. Securely message health care provider and staff (for example, e-mail)?		
e. Download your health information to your computer or mobile device, such as a cell phone or tablet?		
f. Add health information to share with your health care		

provider, such as health concerns, symptoms, and side effects?		
g. Help you make a decision about how to treat an illness or condition?		

14. Do any of your online medical records include the following types of medical information?	Yes	No	Don't know
a. List of health/medical problems			
b. Allergy list			
c. Summaries of your office visit			
d. Clinical notes			
e. Immunization or vaccination history			

15. Have you electronically sent your medical information to...?	Yes	No
a. Another health care provider?		
b. A family member or another person involved with your care?		
c. A service or app that can help manage and store your health information?		

16. In general, how useful is your online medical record for monitoring your health?

Very useful

Somewhat useful

Not very useful

Not at all useful

I do not use my online medical record to monitor my health

Scoring and Interpretation

Refer to the “HINTS5 Cycle 2 Methodology Report” for details on methodology, sampling, and procedures for Cycle 2, sections 4 and 5:

<https://hints.cancer.gov/data/methodology-reports.aspx>

Protocol source: <https://www.phenxtoolkit.org/protocols/view/280401>