



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.

Sickle Cell Transition Intervention Program - Readiness for Transition (TIP-RFT)

Health Care Knowledge and Skills - Medical Skill Set

How much do you know about sickle cell? Do you know how to manage your own health care? How to talk to doctors? Take a few minutes to identify your areas of strength and highlight where there is room to grow!

1. I understand behaviors that can cause a pain episode.

- Strongly Agree
- Somewhat Agree
- Neither Agree nor Disagree
- Somewhat Disagree
- Strongly Disagree
- Not Applicable

Comments:

2. I can answer my doctor's questions during my clinic visits.

- Strongly Agree
- Somewhat Agree
- Neither Agree nor Disagree

- Somewhat Disagree
- Strongly Disagree
- Not Applicable

Comments:

3. I keep track of my medical appointments.

- Strongly Agree
- Somewhat Agree
- Neither Agree nor Disagree
- Somewhat Disagree
- Strongly Disagree
- Not Applicable

Comments:

4. I know how to take my medicines (time, dosage, and frequency) without help.

- Strongly Agree
- Somewhat Agree
- Neither Agree nor Disagree
- Somewhat Disagree
- Strongly Disagree
- Not Applicable

Comments:

5. I am aware of what hydroxyurea is and how it affects sickle cell disease. (If you are not taking this medicine please check: Not Applicable)

- Strongly Agree
- Somewhat Agree
- Neither Agree nor Disagree
- Somewhat Disagree
- Strongly Disagree
- Not Applicable

Comments:

6. I understand how drugs, alcohol, and tobacco usage affect sickle cell disease.

- Strongly Agree
- Somewhat Agree
- Neither Agree nor Disagree
- Somewhat Disagree
- Strongly Disagree
- Not Applicable

Comments:

Education and Vocation Planning - Educational/Vocational Skill Set

Are you ready for your future? Do you have a 504 plan or IEP? Take a few minutes to identify your areas of strength and highlight where there is room to grow!

7. I have a vision for my future.

- Strongly Agree
- Somewhat Agree
- Neither Agree nor Disagree
- Somewhat Disagree
- Strongly Disagree

Not Applicable

Comments:

8. I plan to attend college or obtain post high school training.

Strongly Agree

Somewhat Agree

Neither Agree nor Disagree

Somewhat Disagree

Strongly Disagree

Not Applicable

Comments:

9. I know the types of work situations that could cause problems related to sickle cell disease.

Strongly Agree

Somewhat Agree

Neither Agree nor Disagree

Somewhat Disagree

Strongly Disagree

Not Applicable

Comments:

10. I have talked to my parents about my hopes for the future.

Strongly Agree

Somewhat Agree

- Neither Agree nor Disagree
- Somewhat Disagree
- Strongly Disagree
- Not Applicable

Comments:

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Social Support Skill Set

Do you have the social supports you need? Take a few minutes to identify your areas of strength and highlight where there is room to grow!

11. I participate in activities at school and/or outside the home.

- Strongly Agree
- Somewhat Agree
- Neither Agree nor Disagree
- Somewhat Disagree
- Strongly Disagree
- Not Applicable

Comments:

12. I have friends that I can talk to about sickle cell disease.

- Strongly Agree
- Somewhat Agree
- Neither Agree nor Disagree
- Somewhat Disagree
- Strongly Disagree

Not Applicable

Comments:

13. I have a good social “support” system.

Strongly Agree

Somewhat Agree

Neither Agree nor Disagree

Somewhat Disagree

Strongly Disagree

Not Applicable

Comments:

14. I understand what “healthy relationships” are.

Strongly Agree

Somewhat Agree

Neither Agree nor Disagree

Somewhat Disagree

Strongly Disagree

Not Applicable

Comments:

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Independent Living Skill Set

Are you ready to do it on your own? Take a few minutes to identify your areas of strength and highlight where there is room to grow!

15. I know how to manage money and pay a bill.

- Strongly Agree
- Somewhat Agree
- Neither Agree nor Disagree
- Somewhat Disagree
- Strongly Disagree
- Not Applicable

Comments:

16. I know how to get my prescriptions filled.

- Strongly Agree
- Somewhat Agree
- Neither Agree nor Disagree
- Somewhat Disagree
- Strongly Disagree
- Not Applicable

Comments:

17. I know how to make my own doctors' appointments.

- Strongly Agree
- Somewhat Agree
- Neither Agree nor Disagree
- Somewhat Disagree
- Strongly Disagree

Not Applicable

Comments:

18. I can arrange transportation to my medical appointments on my own.

- Strongly Agree
- Somewhat Agree
- Neither Agree nor Disagree
- Somewhat Disagree
- Strongly Disagree
- Not Applicable

Comments:

19. I know how to write a check.

- Strongly Agree
- Somewhat Agree
- Neither Agree nor Disagree
- Somewhat Disagree
- Strongly Disagree
- Not Applicable

Comments:

20. I know how to use an ATM card.

- Strongly Agree
- Somewhat Agree
- Neither Agree nor Disagree

- Somewhat Disagree
- Strongly Disagree
- Not Applicable

Comments:

21. I have held a full or part-time job.

- Strongly Agree
- Somewhat Agree
- Neither Agree nor Disagree
- Somewhat Disagree
- Strongly Disagree
- Not Applicable

Comments:

22. I go to my doctor's appointments on my own.

- Strongly Agree
- Somewhat Agree
- Neither Agree nor Disagree
- Somewhat Disagree
- Strongly Disagree
- Not Applicable

Comments:

23. What best describes my current living arrangement?

- I live independently in my own apartment, dorm, or private residence

I share an apartment or residence with someone outside of my family

I live with my parents

I live with other family members

I have other living arrangements (Please describe _____

_____)

This checklist is adapted from materials developed by Children's Hospital, Boston as part of the Massachusetts Initiative.

Protocol source: <https://www.phenxtoolkit.org/protocols/view/870901>