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.

The statements below are based on some experiences of people with sickle cell disease (SCD). It is not a test, and there are no "right" or "wrong" responses. Therefore, please respond to each statement as openly and honestly as you possibly can. There is no need to worry about the privacy of your answers or how they might compare to the answers of others, because we are interested in overall views, not individual points of view. Choose a number using the scale below that best indicates your agreement with each statement and write it in the corresponding space. These numbers mean the following:

- 1 = completely false
- 2 = mostly false
- 3 = somewhat false (more false than true)
- 4 = somewhat true (more true than false)
- 5 = mostly true
- 6 = completely true

Social Exclusion

People have physically backed away from me because I have SCD.	
As a rule, telling others that I have SCD has been a mistake.	
People seem to be afraid of me because I have SCD.	

Internalized Stigma

I feel guilty because I have SCD.	
Having SCD makes me feel that I am a bad person.	
I feel I am not as good as others because I have SCD.	

Disclosure Concerns

In many areas of my life, no one knows that I have SCD.	
I am very careful who I tell that I have SCD.	
Telling someone I have SCD is risky.	

Expected Discrimination

People lose jobs when employers learn they have SCD.	

| I worry about people discriminating against me because I have SCD. | |

Scoring

Each item is assigned a value ranging from 1 to 6. A total stigma scale score is computed by adding the values for each of the 11 items. Subscale scores are computed by adding the values for the items that constitute each subscale: Social Exclusion, Internalized Stigma, Disclosure Concerns, and Expected Discrimination. Higher scores indicate greater levels of stigma.

Protocol source: https://www.phenxtoolkit.org/protocols/view/870301