**Instructions**: 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**

1. People have physically backed away from me because I have SCD.

\_\_ 1. completely false

\_\_ 2. mostly false.

\_\_ 3. somewhat false (more false than true)

\_\_ 4. somewhat true (more true than false)

\_\_ 5. somewhat true (more true than false)

\_\_ 6. completely true

1. As a rule, telling others that I have SCD has been a mistake.

\_\_ 1. completely false

\_\_ 2. mostly false.

\_\_ 3. somewhat false (more false than true)

\_\_ 4. somewhat true (more true than false)

\_\_ 5. somewhat true (more true than false)

\_\_ 6. completely true

1. People seem to be afraid of me because I have SCD.

\_\_ 1. completely false

\_\_ 2. mostly false.

\_\_ 3. somewhat false (more false than true)

\_\_ 4. somewhat true (more true than false)

\_\_ 5. somewhat true (more true than false)

\_\_ 6. completely true

**Internalized Stigma**

1. I feel guilty because I have SCD.

\_\_ 1. completely false

\_\_ 2. mostly false.

\_\_ 3. somewhat false (more false than true)

\_\_ 4. somewhat true (more true than false)

\_\_ 5. somewhat true (more true than false)

\_\_ 6. completely true

1. Having SCD makes me feel that I am a bad person.

\_\_ 1. completely false

\_\_ 2. mostly false.

\_\_ 3. somewhat false (more false than true)

\_\_ 4. somewhat true (more true than false)

\_\_ 5. somewhat true (more true than false)

\_\_ 6. completely true

1. I feel I am not as good as others because I have SCD.

\_\_ 1. completely false

\_\_ 2. mostly false.

\_\_ 3. somewhat false (more false than true)

\_\_ 4. somewhat true (more true than false)

\_\_ 5. somewhat true (more true than false)

\_\_ 6. completely true

**Disclosure Concerns**

1. In many areas of my life, no one knows that I have SCD.

\_\_ 1. completely false

\_\_ 2. mostly false.

\_\_ 3. somewhat false (more false than true)

\_\_ 4. somewhat true (more true than false)

\_\_ 5. somewhat true (more true than false)

\_\_ 6. completely true

1. I am very careful who I tell that I have SCD.

\_\_ 1. completely false

\_\_ 2. mostly false.

\_\_ 3. somewhat false (more false than true)

\_\_ 4. somewhat true (more true than false)

\_\_ 5. somewhat true (more true than false)

\_\_ 6. completely true

1. Telling someone I have SCD is risky.

\_\_ 1. completely false

\_\_ 2. mostly false.

\_\_ 3. somewhat false (more false than true)

\_\_ 4. somewhat true (more true than false)

\_\_ 5. somewhat true (more true than false)

\_\_ 6. completely true

**Expected Discrimination**

1. People lose jobs when employers learn they have SCD.

\_\_ 1. completely false

\_\_ 2. mostly false.

\_\_ 3. somewhat false (more false than true)

\_\_ 4. somewhat true (more true than false)

\_\_ 5. somewhat true (more true than false)

\_\_ 6. completely true

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

\_\_ 1. completely false

\_\_ 2. mostly false.

\_\_ 3. somewhat false (more false than true)

\_\_ 4. somewhat true (more true than false)

\_\_ 5. somewhat true (more true than false)

\_\_ 6. completely true

*Refrain from providing the following information to participants:*

References:

Bulgin, D., Asnani, M., Vorderstrasse, A., Royal, C., Pan, W., & Tanabe, P. (2021). Stigma and quality of life in adults with sickle cell disease in Jamaica and the United States. Psychology, Health & Medicine, 1-15. doi:10.1080/13548506.2021.2019808

Holloway, B. M., McGill, L. S., & Bediako, S. M. (2017). Depressive symptoms and sickle cell pain: The moderating role of internalized stigma. Stigma and Health, 2(4), 271-280. doi:10.1037/sah0000060 Protocol source: <https://www.phenxtoolkit.org/protocols/view/870301>

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.