P1068 Bonham Sickle

Q1 Participant ID

Q2 In this section, I am going to ask you question about your general health and physical function.

Q3 Global Health Scale:  Please listen to each question carefully and select a response about your overall health status.  In general, would you say your health is...

* Excellent (1)
* Very Good (2)
* Good (3)
* Fair (4)
* Poor (5)

Q4 In general, how would you rate the quality of your life?

* Excellent (1)
* Very Good (2)
* Good (3)
* Fair (4)
* Poor (5)

Q5 In general, how would you rate your physical health?

* Excellent (1)
* Very Good (2)
* Good (3)
* Fair (4)
* Poor (5)

Q6 In general, how would you rate your mental health, including your mood and your ability to think?

* Excellent (1)
* Very Good (2)
* Good (3)
* Fair (4)
* Poor (5)

Q7 In general, how would you rate your satisfaction with your social activities and relationships?

* Excellent (1)
* Very Good (2)
* Good (3)
* Fair (4)
* Poor (5)

Q8 In general, please rate how well you carry out your usual social activities and roles. (This includes activities at home, at work and in your community, and responsibilities as a parent, child, spouse, employee, friend, etc.)

* Excellent (1)
* Very Good (2)
* Good (3)
* Fair (4)
* Poor (5)

Q454 In the past 7 days, How would you rate your pain on average?

* 0 No pain (1)
* 1 (2)
* 2 (3)
* 3 (4)
* 4 (5)
* 5 (6)
* 6 (7)
* 7 (8)
* 8 (9)
* 9 (10)
* 10 Worst pain imaginable (11)

Q9 To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?

* Excellent (1)
* Very Good (2)
* Good (3)
* Fair (4)
* Poor (5)

Q10 In the past 7 days… How often have you been bothered by emotional problems such as feeling anxious, depressed or irritable?

* Never (1)
* Rarely (2)
* Sometimes (3)
* Often (4)
* Always (5)

Q11 In the past 7 days…How would you rate your fatigue on average?

* None (1)
* Mild (2)
* Moderate (3)
* Severe (4)
* Very severe (5)

Q12 Physical Function:Does your health now limit you in doing vigorous activities, such as running, lifting heavy objects, participating in strenuous sports?

* Not At All (1)
* Very little (2)
* Somewhat (3)
* Quite a lot (4)
* Cannot do (5)

Q13 Does your health now limit you in walking more than a mile?

* Not At All (1)
* Very little (2)
* Somewhat (3)
* Quite a lot (4)
* Cannot do (5)

Q14 Does your health now limit you in climbing one flight of stairs?

* Not At All (1)
* Very little (2)
* Somewhat (3)
* Quite a lot (4)
* Cannot do (5)

Q15 Does your health now limit you in lifting or carrying groceries?

* Not At All (1)
* Very little (2)
* Somewhat (3)
* Quite a lot (4)
* Cannot do (5)

Q16 Does your health now limit you in bending, kneeling, or stooping?

* Not At All (1)
* Very little (2)
* Somewhat (3)
* Quite a lot (4)
* Cannot do (5)

Q17 Are you able to do chores such as vacuuming or yard work?

* Without any difficulty (1)
* With a little difficulty (2)
* With some difficulty (3)
* With much difficulty (4)
* Unable to do (5)

Q18 Are you able to dress yourself, including tying shoelaces and doing buttons?

* Without any difficulty (1)
* With a little difficulty (2)
* With some difficulty (3)
* With much difficulty (4)
* Unable to do (5)

Q19 Are you able to shampoo your hair?

* Without any difficulty (1)
* With a little difficulty (2)
* With some difficulty (3)
* With much difficulty (4)
* Unable to do (5)

Q20 Are you able to wash and dry your own body?

* Without any difficulty (1)
* With a little difficulty (2)
* With some difficulty (3)
* With much difficulty (4)
* Unable to do (5)

Q21 Are you able to get on and off the toilet?

* Without any difficulty (1)
* With a little difficulty (2)
* With some difficulty (3)
* With much difficulty (4)
* Unable to do (5)

Q22 In this section, I will ask you questions about health-related behaviors, like alcohol and tobacco use.

Q23 In your entire life, have you had at least 1 drink of any kind of alcohol, not counting small tastes or sips?

* Yes (1)
* No (2)

Q24 Think specifically about the past 30 days from February 15, 2016, up to and including today. During the past 30 days, on how many days did you drink one or more drinks of an alcoholic beverage?

* Number of days (1) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Don't know / Refused (2)

Answer If Think specifically about the past 30 days from ${date://OtherDate/FL/-1%20month}, up to and including today. During the past 30 days, on how many days did you drink one or more drinks of an al... Number of days Is Greater Than 0

Q25 On the days that you drank during the past 30 days, how many drinks did you usually have each day? Count as a drink a can or bottle of beer; a wine cooler or a glass of wine, champagne, or sherry; a shot of liquor or a mixed drink or cocktail.

* Number of drinks (1) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Don't know (2)

Q26 Have you smoked at least 100 cigarettes in your entire life?Probe: 100 cigarettes = approximately 5 packs

* Yes (1)
* No (2)
* Don't know / Refused (3)

Answer If Have you smoked at least 100 cigarettes in your entire life?Probe: 100 cigarettes = approximately 5 packs Yes Is Selected

Q27 Do you now smoke cigarettes every day, some days, or not at all?

* Every day (1)
* Some days (2)
* Not at all (3)
* Don't know / Refused (4)

Answer If Do you now smoke cigarettes every day, some days, or not at all? Some days Is Selected Or Do you now smoke cigarettes every day, some days, or not at all? Not at all Is Selected

Q28 Have you EVER smoked cigarettes EVERY DAY for at least 6 months?

* Yes (1)
* No (2)
* Don't know / Refused (3)

Answer If Do you now smoke cigarettes every day, some days, or not at all? Every day Is Selected

Q29 On average, about how many cigarettes do you now smoke each day?

* Cigarettes per day (1) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Don't know / Refused (2)

Answer If Do you now smoke cigarettes every day, some days, or not at all? Some days Is Selected

Q30 How many of the past 30 days did you smoke cigarettes?

* Number of days (1) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Don't know (2)

Answer If Do you now smoke cigarettes every day, some days, or not at all? Some days Is Selected

Q31 On average, on those ${q://QID689/ChoiceTextEntryValue/1} days, how many cigarettes did you usually smoke each day?

* Number of cigarettes (1) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Don't know (2)

Answer If Have you smoked at least 100 cigarettes in your entire life? Probe: 100 cigarettes = approximately 5 packs Yes Is Selected And Do you now smoke cigarettes every day, some days, or not at all? Not at all Is Selected

Q32 When you last smoked every day, on average how many cigarettes did you smoke each day?

* Number of cigarettes (1) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Don't know / Refused (2)

Answer If Have you smoked at least 100 cigarettes in your entire life? Probe: 100 cigarettes = approximately 5 packs Yes Is Selected And Do you now smoke cigarettes every day, some days, or not at all? Not at all Is Selected

Q33 When you last smoked fairly regularly, on average how many cigarettes did you smoke each day?

* Number of cigarettes (1) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Don't know / Refused (2)

Q34 Did your mother breast-feed you?

* Yes (1)
* No (2)
* Don't know (3)

Q35 Brief Illness Perception Questionnaire (Sickle cell disease): In this section, I will ask you questions about your sickle cell disease.

Q36 On a scale from 0 to 10, where 0 is no effect at all and 10 is that it affects your life very severely, how much would you say your sickle cell disease affects your life?

* No effect at \_\_\_all\_\_\_\_ 0 (1)
* 1 (2)
* 2 (3)
* 3 (4)
* 4 (5)
* 5 (6)
* 6 (7)
* 7 (8)
* 8 (9)
* 9 (10)
* Affects your life severely 10 (11)

Q37 On a scale from 0 to 10, where 0 is a very short time and 10 is forever, how long do you think your sickle cell disease will continue?

* A very short \_\_\_\_time\_\_\_ 0 (1)
* 1 (2)
* 2 (3)
* 3 (4)
* 4 (5)
* 5 (6)
* 6 (7)
* 7 (8)
* 8 (9)
* 9 (10)
* \_\_\_Forever\_\_\_ 10 (11)

Q38 On a scale from 0 to 10, where 0 is absolutely no control and 10 is an extreme amount of control, how much control do you feel you have over your sickle cell disease?

* Absolutely no \_\_control\_\_ 0 (1)
* 1 (2)
* 2 (3)
* 3 (4)
* 4 (5)
* 5 (6)
* 6 (7)
* 7 (8)
* 8 (9)
* 9 (10)
* Extreme amount of \_\_control\_\_ 10 (11)

Q39 On a scale from 0 to 10, where 0 is not at all helpful and 10 is extremely helpful, how much do you think your treatment can help your sickle cell disease?

* Not at \_\_\_all\_\_\_\_ 0 (1)
* 1 (2)
* 2 (3)
* 3 (4)
* 4 (5)
* 5 (6)
* 6 (7)
* 7 (8)
* 8 (9)
* 9 (10)
* Extremely \_\_\_\_helpful\_\_\_\_\_ 10 (11)

Q40 On a scale from 0 to 10, where 0 is no symptoms at all and 10 is many severe symptoms, how much do you experience symptoms from your sickle cell disease?

* No symptoms at \_\_\_all\_\_\_\_ 0 (1)
* 1 (2)
* 2 (3)
* 3 (4)
* 4 (5)
* 5 (6)
* 6 (7)
* 7 (8)
* 8 (9)
* 9 (10)
* Many severe \_\_\_symptoms\_\_\_ 10 (11)

Q41 On a scale from 0 to 10, where 0 is not at all concerned and 10 is extremely concerned, how concerned are you about your sickle cell disease?

* Not at all \_\_\_concerned\_\_\_ 0 (1)
* 1 (2)
* 2 (3)
* 3 (4)
* 4 (5)
* 5 (6)
* 6 (7)
* 7 (8)
* 8 (9)
* 9 (10)
* Extremely \_\_\_concerned\_\_\_ 10 (11)

Q42 On a scale from 0 to 10, where 0 is do not understand at all and 10 is understand very well, how well do you feel you understand your sickle cell disease?

* Don't understand \_ at all \_\_\_\_\_0\_\_\_\_\_ (1)
* 1 (2)
* 2 (3)
* 3 (4)
* 4 (5)
* 5 (6)
* 6 (7)
* 7 (8)
* 8 (9)
* 9 (10)
* Understand very \_\_\_\_\_\_well\_\_\_\_\_ 10 (11)

Q43 On a scale from 0 to 10, where 0 is not at all affected emotionally and 10 is extremely emotionally affected, how much does your sickle cell disease affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?)

* Not at all affected \_\_\_emotionally\_\_\_ 0 (1)
* 1 (2)
* 2 (3)
* 3 (4)
* 4 (5)
* 5 (6)
* 6 (7)
* 7 (8)
* 8 (9)
* 9 (10)
* Extremely affected \_\_\_emotionally\_\_\_ 10 (11)

Q44 Please list in rank-order the three most important factors that you believe caused your sickle cell disease. The most important causes for me (i.e. genetic condition):

* Cause 1: (1) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Cause 2: (2) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Cause 3: (3) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Q45 Stigma Scale (Sickle cell disease)

Q46 For each question, please answer with strongly disagree, disagree, agree, or strongly agree.  Alienation: You feel out of place in the world because you have sickle cell disease.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q47 Having sickle cell disease has spoiled your life.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q48 People without sickle cell disease could not possibly understand you.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q49 You are embarrassed or ashamed that you have sickle cell disease.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q50 You are disappointed in yourself for having sickle cell disease.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q51 You feel inferior to others who don’t have sickle cell disease.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q52 Discrimination Experience:People discriminate against you because you have sickle cell disease.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q53 Others think that you can’t achieve much in life because you have sickle cell disease.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q54 People ignore you or take you less seriously just because you have sickle cell disease.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q55 People often patronize you, or treat you like a child, just because you have sickle cell disease.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q56 Nobody would be interested in getting close to you because you have sickle cell disease.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q57 Social Withdrawal:You don’t talk about yourself much because you don’t want to burden others with your sickle cell disease.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q58 You don’t socialize as much as you used to because your sickle cell disease might make you look or behave ‘weird.’

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q59 Negative stereotypes about sickle cell disease keep you isolated from the ‘normal’ world.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q60 You stay away from social situations in order to protect your family or friends from embarrassment.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q61 Being around people who don’t have sickle cell disease makes you feel out of place or inadequate.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q62 You avoid getting close to people who don’t have sickle cell disease to avoid rejection.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q63 Stigma Resistance: You feel comfortable being seen in public with a person who obviously has sickle cell disease.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q64 In general, you are able to live life the way you want to.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q65 You can have a good, fulfilling life, despite your sickle cell disease.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q66 People with sickle cell disease make important contributions to society.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q67 Living with sickle cell disease has made you a tough survivor.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q68 Brief Illness Perception Questionnaire (for those with leg ulcers)

Q69 Do you currently have a leg ulcer?

* Yes (1)
* No (2)

If No Is Selected, Then Skip To End of Block

Q70 On a scale from 0 to 10, where 0 is no effect at all and 10 is affects your life severely, how much does your leg ulcer affect your life?

* No affect severely at all 0 (1)
* 1 (2)
* 2 (3)
* 3 (4)
* 4 (5)
* 5 (6)
* 6 (7)
* 7 (8)
* 8 (9)
* 9 (10)
* Affects your life severely 10 (11)

Q71 On a scale from 0 to 10, where 0 is a very short time and 10 is forever, how long do you think your leg ulcer will continue?

* A very short time 0 (1)
* 1 (2)
* 2 (3)
* 3 (4)
* 4 (5)
* 5 (6)
* 6 (7)
* 7 (8)
* 8 (9)
* 9 (10)
* Forever 10 (11)

Q72 On a scale from 0 to 10, where 0 is absolutely no control and 10 is extreme amount of control, how much control do you feel you have over your leg ulcer?

* Absolutely no control 0 (1)
* 1 (2)
* 2 (3)
* 3 (4)
* 4 (5)
* 5 (6)
* 6 (7)
* 7 (8)
* 8 (9)
* 9 (10)
* Extreme amount of control 10 (11)

Q73 On a scale from 0 to 10, where 0 is not at all helpful and 10 is extremely helpful, how much do you think your treatment can help your leg ulcer?

* Not at all 0 (1)
* 1 (2)
* 2 (3)
* 3 (4)
* 4 (5)
* 5 (6)
* 6 (7)
* 7 (8)
* 8 (9)
* 9 (10)
* Extremely helpful 10 (11)

Q74 On a scale from 0 to 10, where 0 is no symptoms at all and 10 is many severe symptoms, how much do you experience symptoms from your leg ulcer?

* No symptoms at all 0 (1)
* 1 (2)
* 2 (3)
* 3 (4)
* 4 (5)
* 5 (6)
* 6 (7)
* 7 (8)
* 8 (9)
* 9 (10)
* Many severe symptoms 10 (11)

Q75 On a scale from 0 to 10, where 0 is not at all concerned and 10 is extremely concerned, how concerned are you about your leg ulcer?

* Not at all concerned 0 (1)
* 1 (2)
* 2 (3)
* 3 (4)
* 4 (5)
* 5 (6)
* 6 (7)
* 7 (8)
* 8 (9)
* 9 (10)
* Extremely concerned 10 (11)

Q76 On a scale from 0 to 10, where 0 is do not understand at all and 10 is understand very clearly, how well do you feel you understand your leg ulcer?

* Don't understand at all 0 (1)
* 1 (2)
* 2 (3)
* 3 (4)
* 4 (5)
* 5 (6)
* 6 (7)
* 7 (8)
* 8 (9)
* 9 (10)
* Understand very clearly 10 (11)

Q77 On a scale from 0 to 10, where 0 is not at all affected emotionally and 10 is extremely affected emotionally, how much does your leg ulcer affect you emotionally?

* Not at all affected emotionally 0 (1)
* 1 (2)
* 2 (3)
* 3 (4)
* 4 (5)
* 5 (6)
* 6 (7)
* 7 (8)
* 8 (9)
* 9 (10)
* Extremely affected emotionally 10 (11)

Q78 Please list in rank-order the three most important factors that you believe caused your leg ulcer.The most important causes for me (i.e. trauma to foot)

* 1. (1) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* 2. (2) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* 3. (3) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Q79 Stigma Scale (for those with leg ulcers)

Q80 For the following questions, please listen to each statement and answer with strongly disagree, disagree, agree, or strongly agree.Alienation: You feel out of place in the world because you have leg ulcers.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q81 Having leg ulcers has spoiled your life.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q82 People without leg ulcers could not possibly understand you.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q83 You are embarrassed or ashamed that you have leg ulcers.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q84 You are disappointed in yourself for having leg ulcers.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q85 You feel inferior to others who don’t have leg ulcers.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q86 Discrimination Experience:People discriminate against you because you have leg ulcers.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q87 Others think that you can’t achieve much in life because you have leg ulcers.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q88 People ignore you or take you less seriously just because you have leg ulcers.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q89 People often patronize you, or treat you like a child, just because you have leg ulcers.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q90 Nobody would be interested in getting close to me because you have leg ulcers.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q91 Social Withdrawal: You don’t talk about yourself much because you don’t want to burden others with your leg ulcers.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q92 You don’t socialize as much as you used to because your leg ulcers might make you look or behave ‘weird.’

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q93 Negative stereotypes about leg ulcers keep you isolated from the ‘normal’ world.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q94 You stay away from social situations in order to protect your family or friends from embarrassment.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q95 Being around people who don’t have leg ulcers makes you feel out of place or inadequate.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q96 You avoid getting close to people who don’t have leg ulcers to avoid rejection.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q97 Stigma Resistance: You feel comfortable being seen in public with a person who obviously has leg ulcers.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q98 In general, you are able to live life the way you want to.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q99 You can have a good, fulfilling life, despite your leg ulcers.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q100 People with leg ulcers make important contributions to society.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q101 Living with leg ulcers has made you a tough survivor.

* Strongly Disagree (1)
* Disagree (2)
* Agree (3)
* Strongly Agree (4)

Q102 Pain Episode Frequency and Severity

Q103 The following questions ask about the frequency and severity of your pain episodes. In the past 12 months, how many sickle cell pain attacks (crises) did you have?

* You did not have a pain attack (crisis) in the past 12 months (1)
* 0 pain attacks (crises) (2)
* 1 pain attack (crisis) (3)
* 2 pain attacks (crises) (4)
* 3 pain attacks (crises) (5)
* 4 or more pain attacks (crises) (6)

Q104 When was your last pain attack (crisis)?

* You never had a pain episode (1)
* You have one right now (2)
* Less than a week ago (3)
* 1-4 weeks ago (4)
* 1-6 months ago (5)
* 7-11 months ago (6)
* 1-5 years ago (7)
* More than 5 years ago (8)

Q105 Using any number from 0 to 10, where 0 is no pain and 10 is the worst imaginable pain, how severe was your pain during your last pain attack (crisis)?

* No pain 0 (1)
* 1 (2)
* 2 (3)
* 3 (4)
* 4 (5)
* 5 (6)
* 6 (7)
* 7 (8)
* 8 (9)
* 9 (10)
* Worst pain imaginable 10 (11)

Q106 Please listen to the following statements and choose the ONE statement that comes closest to what is true for you. How much did your last pain attack (crisis) interfere with your life?

* You’ve never had a pain attack (crisis) (1)
* Not at all, you did everything you usually do (2)
* You had to cut down on some things you usually do (3)
* You could not do most things you usually do (4)
* You could not take care of yourself and needed some help from family or friends (5)
* You could not take care of myself and needed constant care from family, friends, doctors, or nurses (6)

Q107 About how long did your most recent pain attack (crisis) last?

* You’ve never had a pain attack (crisis) (1)
* Less than 1 hour (2)
* 1-12 hours (3)
* 13-23 hours (4)
* 1-3 days (5)
* 4-6 days (6)
* 1-2 weeks (7)
* More than 2 weeks (8)

Q108 Pain Interference:   The following questions ask whether pain interferes with your daily activities in the past 7 days.  Please answer with never, rarely, sometimes, often, or always.   In the past 7 days, how often did you have pain so bad that you could not do anything for a whole day?

* Never (1)
* Rarely (2)
* Sometimes (3)
* Often (4)
* Always (5)

Q109 (In the past 7 days...) How often did you have pain so bad that you could not get out of bed?

* Never (1)
* Rarely (2)
* Sometimes (3)
* Often (4)
* Always (5)

Q110 (In the past 7 days...) How often did you have very severe pain?

* Never (1)
* Rarely (2)
* Sometimes (3)
* Often (4)
* Always (5)

Q111 (In the past 7 days...) How often did you have pain so bad that you had to stop what you were doing?

* Never (1)
* Rarely (2)
* Sometimes (3)
* Often (4)
* Always (5)

Q112 (In the past 7 days...) How often did you have pain so bad that it was hard to finish what you were doing?

* Never (1)
* Rarely (2)
* Sometimes (3)
* Often (4)
* Always (5)

Q113 Sleep

Q114 The following questions ask about your sleep within the past 7 days.   In the past 7 days, how often did you stay up most of the night because you could not fall asleep?

* Never (1)
* Rarely (2)
* Sometimes (3)
* Often (4)
* Always (5)

Q115 (In the past 7 days...) How often was it very easy for you to fall asleep?

* Never (1)
* Rarely (2)
* Sometimes (3)
* Often (4)
* Always (5)

Q116 (In the past 7 days...) How often did you have a lot of trouble falling asleep?

* Never (1)
* Rarely (2)
* Sometimes (3)
* Often (4)
* Always (5)

Q117 (In the past 7 days...) How often did you stay up all night because you could not fall asleep?

* Never (1)
* Rarely (2)
* Sometimes (3)
* Often (4)
* Always (5)

Q118 (In the past 7 days...) How often did you stay up half the night because you could not fall asleep?

* Never (1)
* Rarely (2)
* Sometimes (3)
* Often (4)
* Always (5)

Q119 Health Care & Social Experiences

Q120 Quality of Care for Sickle Cell Disease   The following questions ask about the quality of care you receive.   In the past 12 months, did you try to make an appointment to see a doctor or nurse?

* Yes (1)
* No (2)

Q121 (In the past 12 months...) When you tried to make an appointment to see a doctor or nurse, how often were you able to get one as soon as you wanted?  Would you say never, sometimes, usually, or always?

* Never (1)
* Sometimes (2)
* Usually (3)
* Always (4)

Q122 (In the past 12 months...) How often were you satisfied with the care you received during these scheduled appointments?

* Never (1)
* Sometimes (2)
* Usually (3)
* Always (4)

Q123 Do you have a doctor or nurse you usually see if you need a check up, want advice about a health problem, or get sick or hurt?

* Yes (1)
* No (2)

If No Is Selected, Then Skip To In the past 12 months, did you go to ...

Q124 In the past 12 months, how many visits have you had with this doctor or nurse?

* 0 visits (1)
* 1 visit (2)
* 2 visits (3)
* 3 visits (4)
* 4 or more visits (5)

Q125 (In the past 12 months...) How often did this doctor or nurse explain things in a way that is easy to understand?  Would you say never, sometimes, usually, or always?

* Never (1)
* Sometimes (2)
* Usually (3)
* Always (4)

Q126 (In the past 12 months...) How often did this doctor or nurse listen carefully to you?

* Never (1)
* Sometimes (2)
* Usually (3)
* Always (4)

Q127 (In the past 12 months...) How often did this doctor or nurse treat you with courtesy and respect?

* Never (1)
* Sometimes (2)
* Usually (3)
* Always (4)

Q128 (In the past 12 months...) How often did this doctor or nurse spend enough time with you?

* Never (1)
* Sometimes (2)
* Usually (3)
* Always (4)

Q129 (In the past 12 months...) How often were you satisfied with the care you received from this doctor or nurse?

* Never (1)
* Sometimes (2)
* Usually (3)
* Always (4)

Q130 How much does this doctor or nurse know how sickle cell affects you personally?

* Nothing (1)
* A little bit (2)
* Some (3)
* Quite a bit (4)
* Very much (5)

Q455 Does this doctor or nurse treat a lot of patients with sickle cell disease?

* Yes (1)
* No (2)

Q131 In the past 12 months, did you go to an emergency room for any sickle cell care you needed right away?

* Yes (1)
* No (2)

If No Is Selected, Then Skip To In the past 12 months, how many times...

Q132 In the past 12 months, when you went to the emergency room for this care, how often did you get it as soon as you wanted?

* Never (1)
* Sometimes (2)
* Usually (3)
* Always (4)

Q133 (In the past 12 months...) When you went to the emergency room for this care, how often did the doctors treating you seem to really care about you?

* Never (1)
* Sometimes (2)
* Usually (3)
* Always (4)

Q134 (In the past 12 months...) When you went to the emergency room for this care, how often did the nurses treating you seem to really care about you?

* Never (1)
* Sometimes (2)
* Usually (3)
* Always (4)

Q135 (In the past 12 months...) When you went to the emergency room for this care, how often did the clerks and receptionists treat you with courtesy and respect?

* Never (1)
* Sometimes (2)
* Usually (3)
* Always (4)

Q136 (In the past 12 months...) When you went to the emergency room for this care, how often were you satisfied with the care you received?

* Never (1)
* Sometimes (2)
* Usually (3)
* Always (4)

Q137 (In the past 12 months...) How many times did you manage a pain attack (crisis) at home without going to a doctor, clinic, or hospital?

* You did not have a pain attack (crisis) in the past 12 months (1)
* 0 times (2)
* 1 time (3)
* 2 times (4)
* 3 times (5)
* 4 or more times (6)

Q138 (In the past 12 months...) Did you ever delay or avoid going to an emergency room when you thought you needed care?

* Yes (1)
* No (2)

If No Is Selected, Then Skip To In the past 12 months, how many times...

Q139 How important were bad experiences in the emergency room in your decision to avoid going for care?

* Nothing (1)
* A little bit (2)
* Some (3)
* Quite a bit (4)
* Very much (5)

Q140 How important were health insurance issues in your decision to avoid going for care?

* Nothing (1)
* A little bit (2)
* Some (3)
* Quite a bit (4)
* Very much (5)

Q141 In the past 12 months, how many times did you go to the emergency room because of a pain attack (crisis)?

* 0 times (1)
* 1 time (2)
* 2 times (3)
* 3 times (4)
* 4 or more times (5)

If 0 times Is Selected, Then Skip To Using any number from 0 to 10 where 0...

Q142 (In the past 12 months...) How much were the emergency room doctors and nurses able to help your pain?

* Nothing (1)
* A little bit (2)
* Some (3)
* Quite a bit (4)
* Very much (5)

Q143 (In the past 12 months...) How much did the emergency room doctors and nurses believe that you had very bad sickle cell pain?

* Nothing (1)
* A little bit (2)
* Some (3)
* Quite a bit (4)
* Very much (5)

Q144 (In the past 12 months...) What is the longest you had to wait in the emergency room before your sickle cell pain was treated?

* Less than 5 minutes (1)
* 5 to 15 minutes (2)
* More than 15 minutes but less than 1 hour (3)
* More than 1 hour but less than 2 hours (4)
* More than 2 hours (5)

Q145 Using any number from 0 to 10 where 0 is the worst care possible and 10 is the best care possible, what number would you use to rate your healthcare in the last 12 months?

* Worst care possible 0 (1)
* 1 (2)
* 2 (3)
* 3 (4)
* 4 (5)
* 5 (6)
* 6 (7)
* 7 (8)
* 8 (9)
* 9 (10)
* Best care possible 10 (11)

Q456 Medical Mistrust IndexFor each question, please select the appropriate response.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | Strongly disagree (1) | Disagree (2) | Agree (3) | Strongly Agree (4) |
| You’d better be cautious when dealing with health care organizations (4) |  |  |  |  |
| Patients have sometimes been deceived or misled by health care organizations (3) |  |  |  |  |
| When health care organizations make mistakes they usually cover it up (2) |  |  |  |  |
| Health care organizations have sometimes done harmful experiments on patients without their knowledge (1) |  |  |  |  |
| Health care organizations don’t always keep your information totally private (5) |  |  |  |  |
| Sometimes I wonder if health care organizations really know what they are doing (7) |  |  |  |  |
| Mistakes are common in health care organizations (8) |  |  |  |  |

Q146 Emotional Distress

Q147 The next sets of questions explore your emotional state in the past 7 days.   In the past 7 days, how often did you feel completely hopeless because of your health?

* Never (1)
* Rarely (2)
* Sometimes (3)
* Often (4)
* Always (5)

Q148 (In the past 7 days...) How lonely did you feel because of your health problems?

* Not At All (1)
* A little (2)
* Some (3)
* Quite (4)
* Very (5)

Q149 (In the past 7 days...) How depressed were you about your health problems?

* Not At All (1)
* A little (2)
* Some (3)
* Quite (4)
* Very (5)

Q150 (In the past 7 days...) How much do you worry about getting sick?

* Not At All (1)
* A little (2)
* Some (3)
* Quite (4)
* Very (5)

Q151 (In the past 7 days...) How often were you very worried about needing to go to the hospital?

* Never (1)
* Rarely (2)
* Sometimes (3)
* Often (4)
* Always (5)

Q152 PANAS Scale

Q153 The following questions ask about your mood during the past 30 days.  Please answer with not much/not at all, a little, some, quite a bit, or a lot.  During the past 30 days, how much of the time did you feel….

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Not much or not at all (1) | A little (2) | Some (3) | Quite a bit (4) | A lot (5) |
| Cheerful? (1) |  |  |  |  |  |
| In good spirits? (2) |  |  |  |  |  |
| Extremely happy? (3) |  |  |  |  |  |
| Calm and peaceful? (4) |  |  |  |  |  |
| Satisfied? (5) |  |  |  |  |  |
| Full of life? (6) |  |  |  |  |  |
| Enthusiastic? (7) |  |  |  |  |  |
| Attentive? (8) |  |  |  |  |  |
| Proud? (9) |  |  |  |  |  |
| Active? (10) |  |  |  |  |  |
| Nervous? (11) |  |  |  |  |  |
| Restless or fidgety? (12) |  |  |  |  |  |
| Hopeless? (13) |  |  |  |  |  |
| That everything was an effort? (14) |  |  |  |  |  |
| Worthless? (15) |  |  |  |  |  |
| Afraid? (16) |  |  |  |  |  |
| Jittery? (17) |  |  |  |  |  |
| Irritable? (18) |  |  |  |  |  |
| Ashamed? (19) |  |  |  |  |  |
| Upset? (20) |  |  |  |  |  |

Q154 The Pearlin Self-Mastery Scale:The following questions ask about your ability to be in control of events and ongoing situations in your life. Please answer on a scale of 1-5 with 1 meaning strongly disagree and 5 meaning strongly agree.

Q155 You have little control about things that happen to you.

* Strongly Disagree 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* Strongly Agree 5 (5)

Q156 Some of your problems you can't seem to solve at all.

* Strongly Disagree 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* Strongly Agree 5 (5)

Q157 There is not much that you can do to change important things in your life.

* Strongly Disagree 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* Strongly Agree 5 (5)

Q158 You often feel helpless dealing with the problems of life.

* Strongly Disagree 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* Strongly Agree 5 (5)

Q159 Sometimes you feel like a play ball of life.

* Strongly Disagree 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* Strongly Agree 5 (5)

Q160 You can do almost everything, if you want to.

* Strongly Disagree 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* Strongly Agree 5 (5)

Q161 What will happen in the future considerably depends on yourself.

* Strongly Disagree 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* Strongly Agree 5 (5)

Q162 Perceived Social Support/Conflict

Q163 Do you have a spouse or a partner?

* Yes (1)
* No (2)

If No Is Selected, Then Skip To The next several questions are about ...

Q164 The next several questions are about your spouse/partner.  Please answer a lot, some, a little, or not at all for each of these items.   How much does your spouse or partner really care about you?

* A Lot (1)
* Some (2)
* A little (3)
* Not at all (4)

Q165 How much does he or she understand the way you feel about things?

* A Lot (1)
* Some (2)
* A little (3)
* Not at all (4)

Q166 How much does he or she appreciate you?

* A Lot (1)
* Some (2)
* A little (3)
* Not at all (4)

Q167 How much can you rely on him or her for help if you have a serious problem?

* A Lot (1)
* Some (2)
* A little (3)
* Not at all (4)

Q168 How much can you open up to him or her if you need to talk about your worries?

* A Lot (1)
* Some (2)
* A little (3)
* Not at all (4)

Q169 How much can you relax and be yourself around him or her?

* A Lot (1)
* Some (2)
* A little (3)
* Not at all (4)

Q170 For the next several questions, please answer often, sometimes, rarely, or never for each of these items. How often does your spouse or partner make too many demands on you?

* Often (1)
* Sometimes (2)
* Rarely (3)
* Never (4)

Q171 How often does he or she make you feel tense?

* Often (1)
* Sometimes (2)
* Rarely (3)
* Never (4)

Q172 How often does he or she argue with you?

* Often (1)
* Sometimes (2)
* Rarely (3)
* Never (4)

Q173 How often does he or she criticize you?

* Often (1)
* Sometimes (2)
* Rarely (3)
* Never (4)

Q174 How often does he or she let you down when you are counting on him or her?

* Often (1)
* Sometimes (2)
* Rarely (3)
* Never (4)

Q175 How often does he or she get on your nerves?

* Often (1)
* Sometimes (2)
* Rarely (3)
* Never (4)

Q176 The next several questions are about your family.  Please answer a lot, some, a little, or not at all for each of these items.   Not including your spouse or partner, how much do members of your family really care about you?

* A Lot (1)
* Some (2)
* A little (3)
* Not at all (4)

Q177 How much do they understand the way you feel about things?

* A lot (1)
* Some (2)
* A little (3)
* Not at all (4)

Q178 How much can you rely on them for help if you have a serious problem?

* A lot (1)
* Some (2)
* A little (3)
* Not at all (4)

Q179 How much can you open up to them if you need to talk about your worries?

* A lot (1)
* Some (2)
* A little (3)
* Not at all (4)

Q180 How much do you really care about the members of your family, not including your partner or spouse?

* A lot (1)
* Some (2)
* A little (3)
* Not at all (4)

Q181 How much do you understand the way they feel about things?

* A lot (1)
* Some (2)
* A little (3)
* Not at all (4)

Q182 Please answer often, sometimes, rarely, or never for each of the following items.   Not including your spouse or partner, how often do members of your family make too many demands on you?

* Often (1)
* Sometimes (2)
* Rarely (3)
* Never (4)

Q183 How often do they criticize you?

* Often (1)
* Sometimes (2)
* Rarely (3)
* Never (4)

Q184 How often do they let you down when you are counting on them?

* Often (1)
* Sometimes (2)
* Rarely (3)
* Never (4)

Q185 How often do they get on your nerves?

* Often (1)
* Sometimes (2)
* Rarely (3)
* Never (4)

Q186 The next several questions are about your friends.  Please answer a lot, some, a little, or not at all for each of the following items.   How much do your friends really care about you?

* A Lot (1)
* Some (2)
* A little (3)
* Not at all (4)

Q187 How much do they understand the way you feel about things?

* A Lot (1)
* Some (2)
* A little (3)
* Not at all (4)

Q188 How much can you rely on them for help if you have a serious problem?

* A Lot (1)
* Some (2)
* A little (3)
* Not at all (4)

Q189 How much can you open up to them if you need to talk about your worries?

* A Lot (1)
* Some (2)
* A little (3)
* Not at all (4)

Q190 Please answer often, sometimes, rarely, or never for each of the following items.    How often do your friends make too many demands on you?

* Often (1)
* Sometimes (2)
* Rarely (3)
* Never (4)

Q191 How often do they criticize you?

* Often (1)
* Sometimes (2)
* Rarely (3)
* Never (4)

Q192 How often do they let you down when you are counting on them?

* Often (1)
* Sometimes (2)
* Rarely (3)
* Never (4)

Q193 How often do they get on your nerves?

* Often (1)
* Sometimes (2)
* Rarely (3)
* Never (4)

Q194 Rosenberg Self-esteem Scale

Q195 The following is a list of statements dealing with your general feelings about yourself. Please answer with strongly agree, agree, disagree, or strongly disagree.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | Strongly Agree (1) | Agree (2) | Disagree (3) | Strongly Disagree (4) |
| You feel that you are a person of worth, at least on an equal plane with others (1) |  |  |  |  |
| You feel that you have a number of good qualities. (2) |  |  |  |  |
| All in all, you are inclined to feel that you are a failure. (3) |  |  |  |  |
| You are able to do things as well as most other people. (4) |  |  |  |  |
| You feel you do not have much to be proud of. (5) |  |  |  |  |
| You take a positive attitude toward yourself. (6) |  |  |  |  |
| On the whole, you are satisfied with yourself. (7) |  |  |  |  |
| You wish you could have more respect for yourself. (8) |  |  |  |  |
| You certainly feel useless at times. (9) |  |  |  |  |
| At times you think you are no good at all. (10) |  |  |  |  |

Q196 Stress Measures.I will now ask you questions related to very stressful or traumatic events in your life.  Please answer yes or no if the event has ever happened in your life.

Q197 Acute Events - Lifetime Have you experienced the death of a child of yours?

* Yes (1)
* No (2)

Q198 Have you been a victim of serious physical attack or assault?

* Yes (1)
* No (2)

Q199 Have you experienced a life-threatening illness or accident?

* Yes (1)
* No (2)

Q200 Was there a life-threatening illness or accident to spouse or child?

* Yes (1)
* No (2)

Q201 In the past 5 years, was there a life-threatening illness or accidental injury to someone else close to you?

* Yes (1)
* No (2)

Q202 (In the last 5 years...) Was there a death of someone else close to you?

* Yes (1)
* No (2)

Q203 (In the last 5 years...) Have you Involuntarily lost a job for reasons other than retirement?

* Yes (1)
* No (2)

Q204 (In the past 5 years...) Have you been unemployed and looked for work longer than 3 months?

* Yes (1)
* No (2)

Q205 (In the past 5 years...) Has anyone else in household been unemployed and looking for work for longer than 3 months?

* Yes (1)
* No (2)

Q206 (In the past 5 years...) Have you moved to a worse residence or neighborhood?

* Yes (1)
* No (2)

Q207 (In the past 5 years...) Have you been robbed or had your home burglarized?

* Yes (1)
* No (2)

Q208 (In the past 5 years...) Have you had serious financial problems or difficulties?

* Yes (1)
* No (2)

Q209 (In the past 5 years...) Have you had legal trouble?

* Yes (1)
* No (2)

Q210 (In the past 5 years...) Has anything else bad happened to you that upset you a lot?

* Yes (1)
* No (2)

Q211 (In the past 5 years...) Has anything else bad happened to someone close to you that upset you a lot?

* Yes (1)
* No (2)

Q212 \*\*\* BREAK WILL OCCUR HERE \*\*\*

Q213 During the consent process, you were asked if you were okay with having your hair cut to measure cortisol, which is a biomarker for chronic stress. I will start session two with a few questions about your hair and any hair treatments you have received in the past.

Q214 Are you currently using any type of hair extensions?

* Yes (1)
* No (2)

Q215 Do you use any hair care products?

* Yes (1)
* No (2)

If No Is Selected, Then Skip To Did you agree to provide a hair sampl...

Q216 If yes, which products and how often do you use them?

* Dye (4)
* Perm (5)
* Chemically treated (other) (6)
* Extensions (weave) (7)
* Other: please specify (8) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Answer If If yes, which products and how often do you use them? Dye Is Selected

Q217 How often was your hair dyed?  (i.e. every 6-8 weeks)

Answer If If yes, which products and how often do you use them? Perm Is Selected

Q218 How often was your hair permed?  (i.e. every 6-8 weeks)

Answer If If yes, which products and how often do you use them? Chemically treated (other) Is Selected

Q219 How often was your hair chemically treated with products other than dyes or perms?  (i.e. every 6-8 weeks)

Answer If If yes, which products and how often do you use them? Extensions (weave) Is Selected

Q220 How often did you get extensions or weaves?  (i.e. every 6-8 weeks)

Answer If If yes, which products and how often do you use them? Other: please specify Is Selected

Q221 How often did you receive the other hair treatments?  (i.e. every 6-8 weeks)

Answer If If yes, which products and how often do you use them? Dye Is Selected

Q222 When was the last dye treatment?  (number of days  #)

Answer If If yes, which products and how often do you use them? Perm Is Selected

Q223 When was the last perm treatment?  (number of days  #)

Answer If If yes, which products and how often do you use them? Chemically treated (other) Is Selected

Q224 When was the last chemical treatment other than dye or perm?  (number of days  #)

Answer If If yes, which products and how often do you use them? Extensions (weave) Is Selected

Q225 When was the last extension or weave?  (number of days  #)

Answer If If yes, which products and how often do you use them? Other: please specify Is Selected

Q226 When was the last other treatment?  (number of days  #)

Q227 Did you agree to provide a hair sample for cortisol level analysis?

* Yes (1)
* No (2)

If Yes Is Selected, Then Skip To If yes, what location?

Q228 If you did not agree to provide a hair sample, why?

Q229 If you did not agree to provide a hair sample, is there a smaller amount of hair that you would be willing to provide?

* Yes (1)
* No (2)

Q230 If you did not agree to provide hair sample from your head, would you be willing to provide a hair sample from another part of your body?

* Yes (1)
* No (2)

Answer If Did you agree to provide a hair sample for cortisol level analysis? Yes Is Selected

Q231 If yes, what location?

* Armpit (4)
* Back hair (5)
* Chest hair (6)
* Pubic hair (7)

Q232 Physical Environment

Q233 Please respond to the following set of questions about your physical environment.What is the type of dwelling?

* Detached house (1)
* Duplex/Triplex (2)
* Row house (3)
* Low rise apartment (1-3 floors) (4)
* High rise apartment (>3 floors) (5)
* Mobile home / Trailer (6)
* Other, please specify (7) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Q234 What is the approximate age of your building?(Select one)

* Age of building (1) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Year built (2) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Q235 Years at address When did you start living there?(Select one)

* In this month and year (1) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* At this age (2) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Don't know (3)

Q236 For how many years have you lived there?

Q237 During the past 12 months, has there been water or dampness in your home from broken pipes, leaks, heavy rain, or floods?

* Yes (1)
* No (2)
* Don't know (3)

Q238 Does your home frequently have a mildew odor or musty smell?

* Yes (1)
* No (2)
* Don't know (3)

Q239 Is air conditioning used to cool your home?

* Yes (1)
* No (2)

Q240 Which types of air conditioning units do you use?

* Central unit(s) (1)
* Window or wall unit(s) (2)
* Portable unit(s) (3)

Q241 During which month do you usually start using air conditioning to cool your home?

* January (1)
* February (2)
* March (3)
* April (4)
* May (5)
* June (6)
* July (7)
* August (8)
* September (9)
* October (10)
* November (11)
* December (12)

Q242 During which month do you usually stop using air conditioning to cool your home?

* January (1)
* February (2)
* March (3)
* April (4)
* May (5)
* June (6)
* July (7)
* August (8)
* September (9)
* October (10)
* November (11)
* December (12)

Q243 Which fuels are used for heating your home?

* Gas from underground pipes serving the neighborhood (1)
* Gas from a bottle, tank, or LP (2)
* Electricity (3)
* Fuel oil or kerosene (4)
* Coal or coke (5)
* Wood (6)
* Solar energy (7)
* Other, please specify (8) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* No fuel used (9)
* Don't know (10)

Q244 Does your home have a central heating system with ducts that blow air into most rooms?

* Yes (1)
* No (2)

Q245 During which month do you usually start using heating devices?

* January (1)
* February (2)
* March (3)
* April (4)
* May (5)
* June (6)
* July (7)
* August (8)
* September (9)
* October (10)
* November (11)
* December (12)

Q246 During which month do you usually stop using heating devices?

* January (1)
* February (2)
* March (3)
* April (4)
* May (5)
* June (6)
* July (7)
* August (8)
* September (9)
* October (10)
* November (11)
* December (12)

Q247 In the last 12 months, did any dogs, cats or other small furry animals, such as a rabbit, guinea pig or hamster, live or spend time inside your home?

* Yes (1)
* No (2)
* Refused (3)
* Don't know (4)

Q248 What kind of pet was it?

* Dog (1)
* Cat (2)
* Small furry animal (3)
* Refused (4)
* Don't know (5)

Q249 Current environmental tobacco exposure

Q250 Does anyone who lives with you smoke cigarettes, cigars, or pipes anywhere inside your home?

* Yes (1)
* No (2)
* Refused (3)
* Don't know (4)

Answer If Does anyone who lives here smoke cigarettes, cigars, or pipes anywhere inside this home? Yes Is Selected

Q251 Next, I am going to ask you a few more questions about the people who smoke in your house. You don't have to tell me their names, but can you tell me your relationship to each person and, on average, how many cigarettes they smoke per day inside your home?

|  |  |  |
| --- | --- | --- |
|  | Smokers in your home | |
|  | Relationship (1) | Number of cigarettes per day inside your home (2) |
| Person 1 (1) |  |  |
| Person 2 (4) |  |  |
| Person 3 (5) |  |  |
| Person 4 (6) |  |  |
| Person 5 (7) |  |  |

Q252 At your job or business, how many hours per day can you smell the smoke from other people’s cigarettes, cigars, and/or pipes?

Q253 The next set of questions asks about the importance of religion in your life

Q254 How often do you go to religious services?

* Several times a week (1)
* Once a week (2)
* 2-3 times a month (3)
* About once a month (4)
* Several times a year (5)
* About once or twice a year (6)
* Never (7)

Q255 These questions are designed to find out how much help the people in your congregation would provide if you need it in the future.  If you were ill, how much would the people in your congregation help you out?

* A great deal (1)
* Some (2)
* A little (3)
* None (4)

Q256 If you had a problem or were faced with a difficult situation, how much help and comfort would the people in your congregation give you?

* A great deal (1)
* Some (2)
* A little (3)
* None (4)

Q257 Sometimes the contact we have with others is not always pleasant. How often do the people do the people in your congregation make too many demands on you?

* Very often (1)
* Fairly often (2)
* Once in a while (3)
* Never (4)

Q258 How often are the people in your congregation critical of the things you do?

* Very often (1)
* Often (2)
* Sometimes (3)
* Rarely (4)
* Never (5)

Q259 How spiritual would you say you are?

* Very spiritual (1)
* Moderately spiritual (2)
* Slightly spiritual (3)
* Not spiritual at all (4)

Q260 How much do you try to carry your religion over into all other dealings in your life?

* A great deal (1)
* Quite a bit (2)
* Some (3)
* A little (4)
* Not at all (5)

Q261 Think about how you try to understand and deal with major problems in your life. To what extent is each of the following involved in the way you cope?  Please answer with a great deal, quite a bit, some, a little, not at all or I don’t believe in God.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | A great deal (1) | Quite a bit (2) | Some (3) | A little (4) | Not at all (5) | I don't believe in God (6) |
| You work together with God as partners. (1) |  |  |  |  |  |  |
| You look to God for strength, support, and guidance. (2) |  |  |  |  |  |  |
| You feel God is punishing you for your sins or lack of spirituality. (3) |  |  |  |  |  |  |
| You wonder whether God has abandoned you. (4) |  |  |  |  |  |  |

Q262 For each of the following statements, please tell me whether you agree strongly, agree somewhat, disagree somewhat, or disagree strongly.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | Agree strongly (1) | Agree somewhat (2) | Disagree somewhat (3) | Disagree strongly (4) |
| Your religious or spiritual beliefs give you a reason for living. (1) |  |  |  |  |
| You have trouble finding peace of mind. (2) |  |  |  |  |
| Your religious or spiritual beliefs have given you a sense of direction and purpose in life. (3) |  |  |  |  |
| In the final analysis, you are not so sure that your life adds up to much. (4) |  |  |  |  |

Q263 Are you currently employed?

* Yes (1)
* No (2)

If No Is Selected, Then Skip To How satisfied are you with your/your ...

Q264 On a scale from 1 to 5, where 1 is completely satisfied and 5 is not at all satisfied, how satisfied are you with your job?

* Completely Satisfied 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* Not at all 5 (5)

Q265 Your job requires you to be creative.

* Strongly Disagree 4 (1)
* Disagree 3 (2)
* Agree 2 (3)
* Strongly Agree 1 (4)

Q266 Your job allows you to make a lot of decisions.

* Strongly Disagree 4 (1)
* Disagree 3 (2)
* Agree 2 (3)
* Strongly Agree 1 (4)

Q267 You get to do a variety of different things on your job.

* Strongly Disagree 4 (1)
* Disagree 3 (2)
* Agree 2 (3)
* Strongly Agree 1 (4)

Q268 On a scale from 1 to 4, where 1 is not at all likely and 4 is very likely, how likely is it that during the next couple of years you will involuntarily lose your main job (lose job)?

* Not at all likely 1 (1)
* 2 (2)
* 3 (3)
* Very Likely 4 (4)

Q269 On a scale from 1 to 4, where 1 is not at all likely and 4 is very likely, if you were to lose your main job, what do you think your chances would be of finding another job that paid the same?

* Not at all likely 1 (1)
* 2 (2)
* 3 (3)
* Very Likely 4 (4)

Q270 You are not asked to do an excessive amount of work.

* Strongly Disagree 4 (1)
* Disagree 3 (2)
* Agree 2 (3)
* Strongly Agree 1 (4)

Q271 You have enough time to get the job done.

* Strongly Disagree 4 (1)
* Disagree 3 (2)
* Agree 2 (3)
* Strongly Agree 1 (4)

Q272 You are free from conflicting demands that others make.

* Strongly Disagree 4 (1)
* Disagree 3 (2)
* Agree 2 (3)
* Strongly Agree 1 (4)

Q273 Your job leaves you feeling too tired and stressed after work to participate in the activities with friends and family that you would like to.

* Strongly Disagree 1 (1)
* Disagree 2 (2)
* Agree 3 (3)
* Strongly Agree 4 (4)

Q274 Your job leaves you feeling too tired and stressed after work to participate in the activities in your neighborhood and community that you would like to.

* Strongly Disagree 1 (1)
* Disagree 2 (2)
* Agree 3 (3)
* Strongly Agree 4 (4)

Q275 Do you have a problem with exposure to dangerous chemicals on your job?

* Not exposed 1 (1)
* Exposed but it is a slight problem 2 (2)
* Exposed and it is a great problem 3 (3)

Q276 Do you have a problem with exposure to air pollution from dusts, smoke, gas, fumes, fibers, or other things on your job?

* Not exposed 1 (1)
* Exposed but it is a slight problem 2 (2)
* Exposed and it is a great problem 3 (3)

Q277 To what extent does your job expose you to risk of accident or injury?

* Not exposed 1 (1)
* Exposed but it is a slight problem 2 (2)
* Exposed and it is a great problem 3 (3)

Q278 The following set of questions deals with your current financial situation.  On a scale from 1 to 5, where 1 is completely satisfied and 5 is not at all satisfied, how satisfied are you with your/your family’s present financial situation?

* Completely satisfied 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* Not at all 5 (5)

Q279 On a scale from 1 to 5, where 1 is not difficult at all and 5 is extremely difficult, how difficult is it for you/your family to meet the monthly payments on your bills?

* Not difficult at all 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* Extremely difficult 5 (5)

Q280 In the last year, have you done the following as a result of economic problems to you and your family...Sold possessions or cashed in life insurance to cover day-to-day expenses?

* Yes (1)
* No (2)

Q281 (In the last year, have you done the following as a result of economic problems to you and your family...)Postponed seeing a doctor or other health professional for financial reasons?

* Yes (1)
* No (2)

Q282 (In the last year, have you done the following as a result of economic problems to you and your family...)Been unable to purchase prescribed medications for financial reasons?

* Yes (1)
* No (2)

Q283 (In the last year, have you done the following as a result of economic problems to you and your family...)Borrowed money from friends or relatives to pay for needed everyday expenses?

* Yes (1)
* No (2)

Q284 (In the last year, have you done the following as a result of economic problems to you and your family...)Applied for government assistance such as welfare, food stamps, or Medicaid to help meet everyday expenses?

* Yes (1)
* No (2)

Q285 (In the last year, have you done the following as a result of economic problems to you and your family...)Obtained a loan to consolidate or pay off debt?

* Yes (1)
* No (2)

Q286 (In the last year, have you done the following as a result of economic problems to you and your family...)Moved to cheaper living quarters or moved in with other people because you could not afford to stay where you were?

* Yes (1)
* No (2)

Q287 Using a scale from 1 to 5 with 1 meaning never and 5 meaning at least once a week, please answer the following questions.  In your day-to-day life, how often have been treated with less courtesy or respect than other people?

* Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* At least once a week 5 (5)

Q288 (In your day-to-day life...) How often have you received poorer service than others at a restaurant or stores?

* Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* At least once a week 5 (5)

Q289 (In your day-to-day life...) How often have people acted as if they think you are not smart?

* Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* At least once a week 5 (5)

Q290 (In your day-to-day life...) How often have people acted as if they are afraid of you?

* Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* At least once a week 5 (5)

Q291 (In your day-to-day life...) How often have you been threatened or harassed?

* Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* At least once a week 5 (5)

Q292 (In your day-to-day life...) How often prepare for possible insults from other people before leaving home?

* Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* At least once a week 5 (5)

Q293 (In your day-to-day life...) How often do you feel that you always have to be very careful about your appearance (to get good service or avoid being harassed)?

* Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* At least once a week 5 (5)

Q294 (In your day-to-day life...) How often do you try to avoid certain social situations and places?

* Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* At least once a week 5 (5)

Answer If Are you currently employed? Yes Is Selected

Q295 How often do your supervisor or coworkers make slurs or jokes about racial or ethnic groups?

* Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* At least once a week 5 (5)

Answer If Are you currently employed? Yes Is Selected

Q296 How often do your supervisor or coworkers make slurs or jokes about women?

* Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* At least once a week 5 (5)

Answer If Are you currently employed? Yes Is Selected

Q297 During the last 12 months, how often have you experienced that you have to work twice as hard as others to get the same treatment or evaluation?

* Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* At least once a week 5 (5)

Answer If Are you currently employed? Yes Is Selected

Q298 During the last 12 months, how often have you experienced being watched more closely than other workers?

* Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* At least once a week 5 (5)

Answer If Are you currently employed? Yes Is Selected

Q299 During the last 12 months, how often have you experienced being unfairly humiliated in front of others at work?

* Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* At least once a week 5 (5)

Q300 Do you have a spouse or a partner?

* Yes (1)
* No (2)

If No Is Selected, Then Skip To Do you have children?

Q301 Now I am going to ask you more questions about your spouse or partner.  On a scale from 1 to 5, where 1 is never and 5 is very often, taking everything into consideration, how often do you feel bothered or upset by your marriage/relationship?

* Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* Very often 5 (5)

Q302 On a scale from 1 to 5, where 1 is not at all and 5 is a great deal, how much do you feel your spouse makes too many demands on you?

* Not at all 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* Great deal 5 (5)

Q303 On a scale from 1 to 5, where 1 is not at all and 5 is a great deal, how much is your spouse critical of you or what you do?

* Not at all 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* Great deal 5 (5)

Q304 On a scale from 1 to 5, where 1 is very often and 5 is never, when you and your partner disagree about something, how often do you work things out so that both of you are satisfied?

* Very often 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* Never 5 (5)

Q305 How often does your spouse/partner drink too much?

* All of the time 4 (1)
* Sometimes 3 (2)
* Rarely 2 (3)
* Never 1 (4)

Q306 How often does your spouse/partner push, slap, or hit me?

* All of the time 4 (1)
* Sometimes 3 (2)
* Rarely 2 (3)
* Never 1 (4)

Q307 How often does your spouse/partner waste money the family needs for other things?

* All of the time 4 (1)
* Sometimes 3 (2)
* Rarely 2 (3)
* Never 1 (4)

Q308 How often does your spouse/partner yell or scream at you?

* All of the time 4 (1)
* Sometimes 3 (2)
* Rarely 2 (3)
* Never 1 (4)

Q309 Do you have children?

* Yes (1)
* No (2)

If Yes Is Selected, Then Skip To On average, how much do you feel your...

Q310 On a scale from 1 to 5, where 1 is not at all and 5 is a great deal, how much do you feel your children make too many demands on you?

* Not at all 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* A great deal 5 (5)

Q311 On a scale from 1 to 5, where 1 is never and 5 is almost always, how often do you feel bothered or upset as a parent?

* Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* Almost always 5 (5)

Q312 On a scale from 1 to 5, where 1 is very happy and 5 is not at all happy, how happy are you with the way your children have turned out at this point?

* Very happy 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* Not at all happy 5 (5)

Q313 Please tell state yes or no if any of your children are currently having any of the following problems:Problems with finances?

* Yes (1)
* No (2)

Q314 Problems with job or trouble finding or keeping employment?

* Yes (1)
* No (2)

Q315 Health problems?

* Yes (1)
* No (2)

Q316 Problems with close relationship with others (not counting you or spouse)?

* Yes (1)
* No (2)

Q317 Problems with relationships with you or your spouse?

* Yes (1)
* No (2)

Q453 Anything else?

* Yes (1)
* No (2)

Q318 On a scale from 1 to 5, where 1 is not at all and 5 is a great deal, on average, how much do you feel your friends and relatives make too many demands on you?

* Not at all 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* A great deal 5 (5)

Q319 On a scale from 1 to 5, where 1 is not at all and 5 is a great deal, how much are they critical of you or what you do?

* Not at all 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* A great deal 5 (5)

Q320 Now I am going to ask you questions about your childhood.  Thinking about most of the years until you were 12, how much would you say that your parent(s) (or the adults who raised you) made you feel loved?

* Not at all 5 (1)
* 4 (2)
* 3 (3)
* 3 (4)
* A great deal 1 (5)

Q321 (Thinking about most of the years until you were 12...) How much would you say that they physically threatened or abused you?

* Not at all 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* A great deal 5 (5)

Q322 (Thinking about most of the years until you were 12...) How much would you say they verbally threatened or abused you?

* Not at all 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* A great deal 5 (5)

Q323 (Thinking about most of the years until you were 12...) How much would you say that they participated in school activities?

* Never 5 (1)
* 4 (2)
* 3 (3)
* 2 (4)
* A great deal 1 (5)

Q324 (Thinking about most of the years until you were 12...) Did they or other adults read to you?

* Never 5 (1)
* 4 (2)
* 3 (3)
* 2 (4)
* A great deal 1 (5)

Q325 (Thinking about most of the years until you were 12...) How often did you go to bed at night feeling hungry?

* Never 1 (1)
* Almost never 2 (2)
* Sometimes 3 (3)
* Fairly often 4 (4)
* Very often 5 (5)

Q326 Now I am going to ask you questions about your neighborhood.During past 6 months, how often was there a fight in this neighborhood in which a weapon was used?

* Often 4 (1)
* Sometimes 3 (2)
* Rarely 2 (3)
* Never 1 (4)

Q327 (During past 6 months, how often was there...)A violent argument between neighbors?

* Often 4 (1)
* Sometimes 3 (2)
* Rarely 2 (3)
* Never 1 (4)

Q328 (During past 6 months, how often were there...)Gang fights?

* Often 4 (1)
* Sometimes 3 (2)
* Rarely 2 (3)
* Never 1 (4)

Q329 (During past 6 months, how often was there...)Sexual assault or rape?

* Often 4 (1)
* Sometimes 3 (2)
* Rarely 2 (3)
* Never 1 (4)

Q330 (During past 6 months, how often was there...)Robbery or mugging?

* Often 4 (1)
* Sometimes 3 (2)
* Rarely 2 (3)
* Never 1 (4)

Q331 While you have lived in the neighborhood, has:Anyone ever used violence, such as in a mugging, fight, or sexual assault against you or any member of your household anywhere in your neighborhood?

* Yes (1)
* No (2)

Q332 While you have lived in the neighborhood, has:Your home ever been broken into?

* Yes (1)
* No (2)

Q333 While you have lived in the neighborhood, has:You or another member of your household had anything stolen from your yard, porch, garage, or elsewhere outside your home but on your property?

* Yes (1)
* No (2)

Q334 While you have lived in the neighborhood, has:You or another member of your household had property damaged, including damage to vehicles parked in the street, to the outside of your home, or to other personal property?

* Yes (1)
* No (2)

Q335 How much broken glass or trash on sidewalks and streets do you see in your neighborhood?

* None 1 (1)
* A little 2 (2)
* Some 3 (3)
* A lot/often 4 (4)

Q336 How much graffiti do you see on buildings and walls in your neighborhood?

* None 1 (1)
* A little 2 (2)
* Some 3 (3)
* A lot/often 4 (4)

Q337 How many vacant or deserted houses or storefronts do you see in your neighborhood?

* None 1 (1)
* A little 2 (2)
* Some 3 (3)
* A lot/often 4 (4)

Q338 How often do you see people drinking in public places in your neighborhood?

* None 1 (1)
* A little 2 (2)
* Some 3 (3)
* A lot/often 4 (4)

Q339 How often do you see unsupervised children hanging out on the street in your neighborhood?

* None 1 (1)
* A little 2 (2)
* Some 3 (3)
* A lot/often 4 (4)

Q340 The Cohen Global Perceived Stress Scale

Q341 The questions in this scale ask you about your feelings and thoughts during the last month. Please answer each question with never, almost never, sometimes, fairly often, or very often.  In the last month, how often have you been upset because of something that happened unexpectedly?

* Never (1)
* Almost never (2)
* Sometimes (3)
* Fairly often (4)
* Very Often (5)

Q342 (In the last month...) How often have you felt that you were unable to control the important things in your life?

* Never (1)
* Almost never (2)
* Sometimes (3)
* Fairly often (4)
* Very Often (5)

Q343 (In the last month...) How often have you felt nervous and “stressed”?

* Never (1)
* Almost never (2)
* Sometimes (3)
* Fairly often (4)
* Very Often (5)

Q344 (In the last month...) How often have you felt confident about your ability to handle your personal problems?

* Never (1)
* Almost never (2)
* Sometimes (3)
* Fairly often (4)
* Very Often (5)

Q345 (In the last month...) How often have you felt that things were going your way?

* Never (1)
* Almost never (2)
* Sometimes (3)
* Fairly often (4)
* Very Often (5)

Q346 (In the last month...) How often have you found that you could not cope with all the things that you had to do?

* Never (1)
* Almost never (2)
* Sometimes (3)
* Fairly often (4)
* Very Often (5)

Q347 (In the last month...) How often have you been able to control irritations in your life?

* Never (1)
* Almost never (2)
* Sometimes (3)
* Fairly often (4)
* Very Often (5)

Q348 (In the last month...) How often have you felt that you were on top of things?

* Never (1)
* Almost never (2)
* Sometimes (3)
* Fairly often (4)
* Very Often (5)

Q349 (In the last month...) How often have you been angered because of things that were outside of your control?

* Never (1)
* Almost never (2)
* Sometimes (3)
* Fairly often (4)
* Very Often (5)

Q350 (In the last month...) How often have you felt difficulties were piling up so high that you could not overcome them?

* Never (1)
* Almost never (2)
* Sometimes (3)
* Fairly often (4)
* Very Often (5)

Q351 Racial Identity

Q352 The following statements address your feelings about your racial identity.   Centrality ScaleOverall, being Black has very little to do with how you feel about yourself. (R)

* Strongly disagree        7         (1)
* 6 (2)
* 5 (3)
* 4 (4)
* 3 (5)
* 2 (6)
* Strongly agree 1 (7)

Q353 In general, being Black is an important part of your self-image.

* Strongly disagree        1         (1)
* 2 (2)
* 3 (3)
* 4 (4)
* 5 (5)
* 6 (6)
* Strongly agree 7 (7)

Q354 Your destiny is tied to the destiny of other Black people.

* Strongly disagree        1         (1)
* 2 (2)
* 3 (3)
* 4 (4)
* 5 (5)
* 6 (6)
* Strongly agree 7 (7)

Q355 Being Black is unimportant to your sense of what kind of person you are. (R)

* Strongly disagree        7         (1)
* 6 (2)
* 5 (3)
* 4 (4)
* 3 (5)
* 2 (6)
* Strongly agree 1 (7)

Q356 You have a strong sense of belonging to Black people.

* Strongly disagree        1         (1)
* 2 (2)
* 3 (3)
* 4 (4)
* 5 (5)
* 6 (6)
* Strongly agree 7 (7)

Q357 Being Black is an important reflection of who you are.

* Strongly disagree        1         (1)
* 2 (2)
* 3 (3)
* 4 (4)
* 5 (5)
* 6 (6)
* Strongly agree 7 (7)

Q358 You have a strong attachment to other Black people.

* Strongly disagree        1         (1)
* 2 (2)
* 3 (3)
* 4 (4)
* 5 (5)
* 6 (6)
* Strongly agree 7 (7)

Q359 Being Black is not a major factor in your social relationships. (R)

* Strongly disagree        7         (1)
* 6 (2)
* 5 (3)
* 4 (4)
* 3 (5)
* 2 (6)
* Strongly agree 1 (7)

Q360 Brief Resilience Scale

Q361 The following questions ask about your resilience in dealing with stressful life events.  Please respond to the following statements with strong disagree, disagree, neutral, agree, strongly agree.  You tend to bounce back quickly after hard times.

* Strongly Disagree (1)
* Disagree (2)
* Neutral (3)
* Agree (4)
* Strongly Agree (5)

Q362 You have a hard time making it through stressful events. (R)

* Strongly Disagree (1)
* Disagree (2)
* Neutral (3)
* Agree (4)
* Strongly Agree (5)

Q363 It does not take you long to recover from a stressful event.

* Strongly Disagree (1)
* Disagree (2)
* Neutral (3)
* Agree (4)
* Strongly Agree (5)

Q364 It is hard for you to snap back when something bad happens. (R)

* Strongly Disagree (1)
* Disagree (2)
* Neutral (3)
* Agree (4)
* Strongly Agree (5)

Q365 You usually come through difficult times with little trouble.

* Strongly Disagree (1)
* Disagree (2)
* Neutral (3)
* Agree (4)
* Strongly Agree (5)

Q366 You tend to take a long time to get over set-backs in your life. (R)

* Strongly Disagree (1)
* Disagree (2)
* Neutral (3)
* Agree (4)
* Strongly Agree (5)

Q367 Self-Compassion Scale

Q368 The following questions are about self-compassion.  Please consider how you respond in each of the following situations.  Answer on a scale of 1 to 6 with 1 meaning almost never and 6 meaning almost always.  You are disapproving and judgmental about your own flaws and inadequacies.

* Almost Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* 5 (5)
* Almost always 6 (6)

Q369 When you are feeling down you tend to obsess and fixate on everything that’s wrong.

* Almost Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* 5 (5)
* Almost always 6 (6)

Q370 When things are going badly for you, you see the difficulties as part of life that everyone goes through.

* Almost Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* 5 (5)
* Almost always 6 (6)

Q371 When you think about your inadequacies, it tends to make you feel more separate and cut off from the rest of the world.

* Almost Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* 5 (5)
* Almost always 6 (6)

Q372 You try to be loving towards yourself when you are feeling emotional pain.

* Almost Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* 5 (5)
* Almost always 6 (6)

Q373 When you fail at something important to you, you become consumed by feelings of inadequacy.

* Almost Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* 5 (5)
* Almost always 6 (6)

Q374 When you are down and out, you remind yourself that there are lots of other people in the world feeling like you are.

* Almost Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* 5 (5)
* Almost always 6 (6)

Q375 When times are really difficult, you tend to be tough on yourself.

* Almost Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* 5 (5)
* Almost always 6 (6)

Q376 When something upsets you, you try to keep your emotions in balance.

* Almost Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* 5 (5)
* Almost always 6 (6)

Q377 When you feel inadequate in some way, you try to remind yourself that feelings of inadequacy are shared by most people.

* Almost Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* 5 (5)
* Almost always 6 (6)

Q378 You are intolerant and impatient towards those aspects of your personality you don't like.

* Almost Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* 5 (5)
* Almost always 6 (6)

Q379 When you are going through a very hard time, you give yourself the caring and tenderness you need.

* Almost Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* 5 (5)
* Almost always 6 (6)

Q380 When you are feeling down, you tend to feel like most other people are probably happier than you are.

* Almost Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* 5 (5)
* Almost always 6 (6)

Q381 When something painful happens you try to take a balanced view of the situation.

* Almost Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* 5 (5)
* Almost always 6 (6)

Q382 You try to see your failings as part of the human condition.

* Almost Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* 5 (5)
* Almost always 6 (6)

Q383 When you see aspects of yourself that you don’t like, you get down on yourself.

* Almost Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* 5 (5)
* Almost always 6 (6)

Q384 When you fail at something important to yourself, you try to keep things in perspective.

* Almost Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* 5 (5)
* Almost always 6 (6)

Q385 When you are really struggling, you tend to feel like other people must be having an easier time of it.

* Almost Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* 5 (5)
* Almost always 6 (6)

Q386 You are kind to yourself when you are experiencing suffering.

* Almost Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* 5 (5)
* Almost always 6 (6)

Q387 When something upsets you, you get carried away with your feelings.

* Almost Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* 5 (5)
* Almost always 6 (6)

Q388 You can be a bit cold-hearted towards yourself when you are experiencing suffering.

* Almost Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* 5 (5)
* Almost always 6 (6)

Q389 When you are feeling down you try to approach your feelings with curiosity and openness.

* Almost Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* 5 (5)
* Almost always 6 (6)

Q390 You are tolerant of your own flaws and inadequacies.

* Almost Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* 5 (5)
* Almost always 6 (6)

Q391 When something painful happens you tend to blow the incident out of proportion.

* Almost Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* 5 (5)
* Almost always 6 (6)

Q392 When you fail at something that's important to you, you tend to feel alone in your failure.

* Almost Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* 5 (5)
* Almost always 6 (6)

Q393 You try to be understanding and patient towards those aspects of your personality you don't like.

* Almost Never 1 (1)
* 2 (2)
* 3 (3)
* 4 (4)
* 5 (5)
* Almost always 6 (6)

Q394 Social Desirability Scale

Q395 The following statements ask about your relationships with others.  Please answer with definitely true, mostly true, don't know, mostly false, or definitely false.  You are always courteous even to people who are disagreeable.

* Definitely True (1)
* Mostly true (2)
* Don’t know (3)
* Mostly false (4)
* Definitely False (5)

Q396 There have been occasions when you took a advantage of someone.

* Definitely True (1)
* Mostly true (2)
* Don’t know (3)
* Mostly false (4)
* Definitely False (5)

Q397 You sometimes try to get even rather than a forgive and forget.

* Definitely True (1)
* Mostly true (2)
* Don’t know (3)
* Mostly false (4)
* Definitely False (5)

Q398 You sometimes feel resentful when you don’t get your way.

* Definitely True (1)
* Mostly true (2)
* Don’t know (3)
* Mostly false (4)
* Definitely False (5)

Q399 No matter who you are talking to, you are always a good listener.

* Definitely True (1)
* Mostly true (2)
* Don’t know (3)
* Mostly false (4)
* Definitely False (5)

Q400 John Henryism Scale

Q401 The next set of questions ask about your ability to cope during prolonged exposures to stress.  Please consider each statement and answer with the following scale: completely false, somewhat false, somewhat true, or completely true.   You have always felt that you could make of your life pretty much what you wanted to make of it.

* Completely false (1)
* Somewhat false (2)
* Somewhat true (3)
* Completely true (4)
* Don’t know (5)
* Refused (6)

Q402 Once you make up your mind to do something, you stay with it until the job is completely done.

* Completely false (1)
* Somewhat false (2)
* Somewhat true (3)
* Completely true (4)
* Don’t know (5)
* Refused (6)

Q403 You like doing things that other people thought could not be done.

* Completely false (1)
* Somewhat false (2)
* Somewhat true (3)
* Completely true (4)
* Don’t know (5)
* Refused (6)

Q404 When things don’t go the way you want them to, that just makes you work even harder.

* Completely false (1)
* Somewhat false (2)
* Somewhat true (3)
* Completely true (4)
* Don’t know (5)
* Refused (6)

Q405 Sometimes you feel that if anything is going to be done right, you have to do it yourself.

* Completely false (1)
* Somewhat false (2)
* Somewhat true (3)
* Completely true (4)
* Don’t know (5)
* Refused (6)

Q406 It’s not always easy, but you manage to find a way to do the things you really need to get done.

* Completely false (1)
* Somewhat false (2)
* Somewhat true (3)
* Completely true (4)
* Don’t know (5)
* Refused (6)

Q407 Very seldom have you been disappointed by the results of your hard work.

* Completely false (1)
* Somewhat false (2)
* Somewhat true (3)
* Completely true (4)
* Don’t know (5)
* Refused (6)

Q408 You feel that you are the kind of individual who stands up for what you believe in, regardless of the consequences.

* Completely false (1)
* Somewhat false (2)
* Somewhat true (3)
* Completely true (4)
* Don’t know (5)
* Refused (6)

Q409 In the past, even when things got really tough, you never lost sight of your goals.

* Completely false (1)
* Somewhat false (2)
* Somewhat true (3)
* Completely true (4)
* Don’t know (5)
* Refused (6)

Q410 It’s important for you to be able to do things the way you want to do them rather than the way other people want you to do them.

* Completely false (1)
* Somewhat false (2)
* Somewhat true (3)
* Completely true (4)
* Don’t know (5)
* Refused (6)

Q411 You don’t let your personal feelings get in the way of doing a job.

* Completely false (1)
* Somewhat false (2)
* Somewhat true (3)
* Completely true (4)
* Don’t know (5)
* Refused (6)

Q412 Hard work has really helped you to get ahead in life.

* Completely false (1)
* Somewhat false (2)
* Somewhat true (3)
* Completely true (4)
* Don’t know (5)
* Refused (6)

Q457 Perceived Stressful Discrimination: RACISM or DISCRIMINATION from non-African Americans   In general, have you ever experienced RACISM or DISCRIMINATION from non-African Americans in any aspect of your life such as work, school, or shopping because of your skin color and race that was stressful to you?

* Yes (1)
* No (2)
* Don't know / Not sure (3)
* Refused (4)

Q458 In general, have you ever experienced RACISM or DISCRIMINATION on your JOB from non-African Americans because of your skin color and race that was stressful to you?

* Yes (1)
* No (2)
* Don't know / Not sure (3)
* Refused (4)

Q459 In general, do you CURRENTLY experience RACISM or DISCRIMINATION on your JOB from non-African Americans because of your skin color and race that was stressful to you?

* Yes (1)
* No (2)
* Don't know / Not sure (3)
* Refused (4)

Q460 Please rank YOUR stress level when your experience racism or discrimination from non-African Americans because of your skin color and race. (Only one response must be selected)

* Not stress (1)
* Low stress (2)
* Moderate stress (3)
* High stress (4)
* Very high stress (5)
* Not applicable (6)
* Don't know / Not sure (7)
* Refused (8)

Q461 Please rank YOUR belief about the level of your ability to deal with a racial or discriminatory encounter from non-African Americans because of your skin color and race (Only one response must be selected)

* Very low ability (1)
* Low ability (2)
* Moderate ability (3)
* High ability (4)
* Very high ability (5)
* Not Applicable (6)
* Don’t know/Not sure (7)
* Refused (8)

Q462 If you are currently employed or temporarily unemployed, please rank YOUR stress level in general when you experience racism or discrimination AT WORK from non-African Americans because of your skin color and race (Only one response must be selected )

* Not stress (1)
* Low stress (2)
* Moderate stress (3)
* High stress (4)
* Very high stress (5)
* Not applicable (6)
* Don’t know/Not sure (7)
* Refused (8)

Q463 If you are CURRENTLY employed or temporarily unemployed, please rank YOUR belief about the level of your ability to deal with a racial or discriminatory encounter AT WORK  from non-African Americans because of your skin color and race (Only one response must be selected)

* Very low ability (1)
* Low ability (2)
* Moderate ability (3)
* High ability (4)
* Very high ability (5)
* Not Applicable (6)
* Don’t know/Not sure (7)
* Refused (8)

Q464 In general, have you ever experienced DISCRIMINATION from OTHER African Americans in any aspect of your life such as work, school, or shopping because of your skin color that was stressful to you?

* Yes (1)
* No (2)
* Don't know / Not sure (3)
* Refused (4)

Q465 In general, have you ever experienced DISCRIMINATION on your JOB from OTHER African Americans because of your skin color that was stressful to you?

* Yes (1)
* No (2)
* Don't know / Not sure (3)
* Refused (4)

Q466 In general, do you CURRENTLY experience DISCRIMINATION on your JOB from OTHER African Americans because of your skin color that was stressful to you?

* Yes (1)
* No (2)
* Don't know / Not Sure (3)
* Refused (4)

Q467 Please rank your level of stress when you experience discrimination from ANOTHER African Americans because of your skin color (Only one response must be selected).

* Not stress (1)
* Low stress (2)
* Moderate stress (3)
* High stress (4)
* Very high stress (5)
* Not applicable (6)
* Don’t know/Not sure (7)
* Refused (8)

Q468 Please rank YOUR belief about the level of your ability to deal with discriminatory encounter from ANOTHER African Americans because of your skin color (Only one response must be selected)

* Very low ability (1)
* Low ability (2)
* Moderate ability (3)
* High ability (4)
* Very high ability (5)
* Not Applicable (6)
* Don’t know/Not sure (7)
* Refused (8)

Q469 If you are currently employed or temporarily unemployed, in general please rank your stress level when you experience a DISCRIMINATION AT WORK from OTHER African Americans because of your skin color (Only one response must be selected)

* Not stress (1)
* Low stress (2)
* Moderate stress (3)
* High stress (4)
* Very high stress (5)
* Not applicable (6)
* Don’t know/Not sure (7)
* Refused (8)

Q470 If you are currently employed or temporarily unemployed, please rank YOUR belief about the level of your ability to deal with discriminatory encounter AT WORK  from  ANOTHER African Americans because of your skin color (Only one response must be selected)

* Very low ability (1)
* Low ability (2)
* Moderate ability (3)
* High ability (4)
* Very high ability (5)
* Not Applicable (6)
* Don’t know/Not sure (7)
* Refused (8)

Q413 Modified Perceptions of Participation in Clinical Research (PPCR)

Q414 Please tell me how much you disagree or agree with the following statements about clinical research.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Strongly disagree (1) | Disagree (2) | Neither Agree nor Disagree (3) | Agree (4) | Strongly Agree (5) |
| Clinical trials are a necessary way to learn about treatments (1) |  |  |  |  |  |
| It is important for people to take part in genetic research (2) |  |  |  |  |  |
| Participation in a genetic research can help your family and you (3) |  |  |  |  |  |
| Participation in a genetic research can help future generations (4) |  |  |  |  |  |

Q415 Have you previously participated in research for sickle cell disease?

* Yes (1)
* No (2)
* Don't know (3)

Q416 Before this study have you ever participated in a microbiome and genetic research study for sickle cell disease?

* Yes (1)
* No (2)
* Don't know (3)

Q417 Please tell me how much you disagree or agree with the following statement.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Strongly disagree (1) | Disagree (2) | Neither Agree nor Disagree (3) | Agree (4) | Strongly Agree (5) |
| Genetic research is a necessary way to learn about treatments for sickle cell disease? (1) |  |  |  |  |  |

Q418 Do you think there are opportunities for individuals living with sickle cell disease to take part in genetic research?

* Yes (1)
* No (2)
* Don't know (3)

Q419 Has your doctor ever talked to you about participating in a research study, for example, an observational study, as a patient in a clinical trial,  genetic or genomic study, or as a participant in a long term study where you are periodically interviewed about your health?

* Yes (1)
* No (2)
* Don't know (3)

Q420 Before this study, have you ever participated in a medical research study?

* Yes (1)
* No (2)
* Don't know (3)

Q421 Before this study have you ever participated in a genetic or genomic research study?

* Yes (1)
* No (2)
* Don't know (3)

Q422 Please listen to the following statements and choose which of the following, if any, are reasons you decided to participate in a clinical research study.

* To advance medicine or science (1)
* To help others with the condition (2)
* To obtain education about treatment/improving my health (3)
* To obtain better treatment for my condition (4)
* You were curious about the specifics of the study (5)
* The information you read, saw, or had heard about the study influenced you (6)
* Your doctor recommended the study (7)
* To earn extra money (8)
* To obtain free medication (9)

Q423 That is all the questions we have today.  Thank you very much for your participation and patience.  [Collect Beck Depression Inventory completed questionnaire, provide directions to leave office, etc]

Q424 Beck Depression InventoryThis section should be completed after the respondent has left the interview room from the completed paper questionnaire.  Please enter the responses to the Beck Depression Inventory questionnaire below.

Q425 Please read each group of statements carefully, and then pick out the one statement in each group that best describes the way you have been feeling during the past two weeks, including today.   Sadness

* I do not feel sad. (1)
* I feel sad much of the time. (2)
* I am sad all the time. (3)
* I am so sad or unhappy that I can’t stand it. (4)

Q426 Pessimism

* I am not discouraged about my future. (1)
* I feel more discouraged about my future than I used to be. (2)
* I do not expect things to work out for me. (3)
* I feel my future is hopeless and will only get worse. (4)

Q427 Past failure

* I do not feel like a failure. (1)
* I have failed more than I should have. (2)
* As I look back, I see a lot of failures. (3)
* I feel I am a total failure as a person. (4)

Q428 Loss of Pleasure

* I get as much pleasure as I ever did from the things I enjoy. (1)
* I don’t enjoy things as much as I used to. (2)
* I get very little pleasure from the things I used to enjoy. (3)
* I can’t get any pleasure from the things I used to enjoy. (4)

Q429 Guilty Feelings

* I don’t feel particularly guilty. (1)
* I feel guilty over many things I have done or should have done. (2)
* I feel quite guilty most of the time. (3)
* I feel guilty all of the time. (4)

Q430 Punishment Feelings

* I don’t feel like I am being punished. (1)
* I feel I may be punished. (2)
* I expect to be punished. (3)
* I feel I am being punished. (4)

Q431 Self-Dislike

* I feel the same about myself as ever. (1)
* I have lost confidence in myself. (2)
* I am disappointed in myself. (3)
* I dislike myself. (4)

Q432 Self-Criticalness

* I don’t criticize or blame myself more than usual. (1)
* I am more critical of myself than I used to be. (2)
* I criticize myself for all of my faults. (3)
* I blame myself for everything bad that happens. (4)

Q433 Suicidal Thoughts or Wishes

* I don’t have any thoughts of killing myself. (1)
* I have thoughts of killing myself, but I would not carry them out. (2)
* I would like to kill myself. (3)
* I would kill myself if I had the chance. (4)

Q434 Crying

* I don’t cry anymore than I used to. (1)
* I cry more than I used to. (2)
* I cry over every little thing. (3)
* I feel like crying, but I can’t. (4)

Q435 Agitation

* I am no more restless or wound up than usual. (1)
* I feel more restless or wound up than usual. (2)
* I am so restless or agitated that it’s hard to stay still. (3)
* I am so restless or agitated that I have to keep moving or doing something. (4)

Q436 Loss of Interest

* I have not lost interested in other people or activities. (1)
* I am less interested in other people or things than before. (2)
* I have lost most of my interest in other people or things. (3)
* It’s hard to get interested in anything. (4)

Q437 Indecisiveness

* I make decisions about as well as ever. (1)
* I find it more difficult to make decisions than usual. (2)
* I have much greater difficulty in making decisions than I used to. (3)
* I have trouble making any decisions. (4)

Q438 Worthlessness

* I do not feel I am worthless. (1)
* I don’t consider myself as worthwhile and useful as I used to. (2)
* I feel more worthless as compared to other people. (3)
* I feel utterly worthless. (4)

Q439 Loss of Energy

* I have as much energy as ever. (1)
* I have less energy than I used to have. (2)
* I don’t have enough energy to do very much. (3)
* I don’t have enough energy to do anything. (4)

Q440 Changes in Sleeping Pattern

* I have not experienced any change in my sleeping pattern. (1)
* I sleep somewhat more than usual. (2)
* I sleep somewhat less than usual. (3)
* I sleep a lot more than usual. (4)
* I sleep a lot less than usual. (5)
* I sleep most of the day. (6)
* I wake up 1-2 hours early and can’t get back to sleep. (7)

Q441 Irritability

* I am no more irritable than usual. (1)
* I am more irritable than usual. (2)
* I am much more irritable than usual. (3)
* I am irritable all the time. (4)

Q442 Changes in Appetite

* I have not experienced any change in my appetite. (1)
* My appetite is somewhat less than usual. (2)
* My appetite is somewhat greater than usual. (3)
* My appetite is much less than before. (4)
* My appetite is much greater than usual. (5)
* I have no appetite at all. (6)
* I crave food all the time. (7)

Q443 Concentration Difficulty

* I can concentrate as well as ever. (1)
* I can’t concentrate as well as usual. (2)
* It’s hard to keep my mind on anything for very long. (3)
* I find I can’t concentrate on anything. (4)

Q444 Tiredness or Fatigue

* I am no more tired or fatigued than usual. (1)
* I get more tired or fatigued more easily than usual. (2)
* I am too tired or fatigued to do a lot of the things I used to do. (3)
* I am too tired or fatigued to do most of the things I used to do. (4)

Q445 Loss of Interest in Sex

* I have not noticed any recent change in my interest in sex. (1)
* I am less interested in sex than I used to be. (2)
* I am much less interested in sex now. (3)
* I have lost interest in sex completely. (4)

Q452 The Beck module is the last set of questions before the survey is finalized.  If you forget to enter the Beck module or realize you need to change something minor after you submit the survey, please write Nathan an email at nrjones@ssc.wisc.edu with the case ID and ask him to send you a link to 'Retake the survey'.  If there is a more substantial problem, you can also ask him to send you a link to 'Retake the survey as a new response' which will preserve the original data AND the updated version for reference in the future.  Is this survey ready for final submission?

* Yes (1)
* No (2)