**NIH/NHGRI/SBRB INSIGHTS/SCD Study**

**List of Social Measures & Corresponding Survey Questions (University of Wisconsin Online Version)**

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| **Measure Name(s)** | **Variable Name (Survey Dataset)** | **Survey Q #** | | **Score**  **(Notes/Reference/Comm, etc)** | |
| **1. Global Health Questions**  **-** Global Health Score  - Global Mental Health  Score | ghs\_Health  ghs\_Mntl | **5, 9,11, (454 or 454alt\*)**  **4, 6, 7, 10** | | 8 items (gives two components: global health score and mental health score)  - PROMIS Instrument.  **Guidelines for scoring**:  -Reverse code 5, 9, 11, 454 so that higher scores indicate better standing (e.g. Excellent=5 points, Never=1 point)  -Sum scores for all individual items for each scale component (e.g. ghs\_health=Q5+Q9+Q11+Q454\*)  -Raw scores are then converted into T-score values.  -T-score distributions are standardized such that a 50 represents the average, and the SD is 10.  -See conversion table in manual  -Note: conversion table only works when all items are answered.  **Note on Scale/Interpretation**:  -\*454alt is used as a substitute when participant has a missing response to Q454.  -A high score always represents more of the concept being measured.  -T-scores can be used to make comparisons to the general population. For example: a person who has a t-score of 60 for health or mntl is 1 SD more healthy than the general population.  **Manual**:  <http://www.assessmentcenter.net/documents/Scoring%20PROMIS%20Global%20short%20form.pdf> | |
| 1a. Physical Function | ghs\_physical | **12 – 21** | | 10-items PROMIS Instrument.  **Guidelines/Interpretation**:  **To score:**  -Response pattern scoring is the preferred, more accurate method. Otherwise:  -At least 5 out of 10 items have to be answered.  -Reverse scales for Q12 – Q21 so higher scores reflect higher standing (i.e. ‘Cannot do’=1).  -Sum the response scores, then multiply by the total number of items in the scale (10) and divide by the number of items that were answered to obtain a raw score [(raw sum X total number of items)/ number answered].  -If score is a fraction, round to the nearest whole number  -Use summed raw score and Appendix I in manual to obtain the standard T-score (the final score). This allows for comparison to the US general population.  **Notes on Interpretation**:  -Measures self-reported current physical capability rather than actual performance.  -Higher raw scores indicate higher functioning abilities (better able to shampoo, vacuum, walk, etc)  -Raw scores are standardized into T-scores (standard mean based on US population is 50 (SD 10)) , which is the final score.  -Higher PROMIS T-score presents more of the concept being measured: so, 60 means 1 SD better than avg. for physical function.  **Manual (Pages 4-6 & p. 10-11)**:  <http://www.assessmentcenter.net/documents/PROMIS%20Physical%20Function%20Scoring%20Manual.pdf> | |
| 1b. Brief Illness Perception | ghs\_bipercep  ghs\_bipercepLU | **36-43**    **70-77🡪 (for those with leg ulcers)** | | 8-item +1 question (free text) on causal factors for SCD  -Score represents perceived threat level of illness (higher score=more threatening view of the illness)  **To Score**:  -Recode individual item scales from 1-11 to a score of 0-10  -Reverse score for Q38, Q39, Q42, Q72, Q73, Q76  -Sum all items for overall score  -Recommended that we check the internal consistency of this scale for our study  **Manual**:  -See Microsoft word document under scoring Brief IPQ section:  <http://www.uib.no/ipq/> | |
| 1c. Stigma Scale for SCD:  -Alienation  -Discrimination  Experience    -Social Withdrawal  -Stigma Resistance | Stigma\_alienation  Stigma\_discrim  Stigma\_swithdraw  Stigma\_resistance | **46-51**  **52-56**  **57-62**  **63-67** | | 22-item (measures the respondents’ internalized stigma due to their SCD Health Condition)  **Score/Interpretation**:  -Calculate average for each factor: e.g. alienation: (sum Q46 thru Q51)/6  -Higher numbers correlate to greater stigma, except for resistance, where higher scores indicate more effort to resist stigma  - Consider running a principal component analysis (PCA) to examine response clusters.  **Manual**:  Please refer to attached guidelines by Dr. Valerie Purdie-Vaughns (Stigma Measures); see page 2 of attachment. | |
| 1d. Stigma Scale for those  with Leg Ulcers:  - Alienation  -Discrimination  Experience  -Social Withdrawal  -Stigma Resistance | LUstigma\_alienation  LUstigma\_disc  LUstigma\_swithdrawal  LUstigma\_resistance | **80-85**  **86-90**  **91-96**  **97-101** | | 22-items (measures the respondents’ internalized stigma due to their Leg Ulcer Condition)  **Scoring and Manual**:  Same as above (1c : Stigma Scale for SCD) | |
| 1e. ASCQ-Me Pain Episode:  -Pain Episode  Frequency  - Pain Episode  Severity | Ascq\_PainFreq  Ascq\_painSev | **103-104**  **105-107** | | 5-items total: Gives two composite scores: Frequency and Severity.  **Scoring & Interpretation**:  -Cannot be scored if any response is missing on any of the items  -Scale all items so lowest minimum score is 0  -Reverse code q104 so higher scores mean more frequent pain episodes  -Sum the scores of individual items to obtain a raw score. The Pain Frequency ranges 0 – 12 and pain severity ranges 0-22  -Raw scores should be standardized to make comparisons to pain severity to the ASCQ-ME Field respondents’ scores. They are standardized to 50 w/SD of 10, and scores are comparative to the SCD population of the ASCQ-ME field respondents (not a general US population)  - Higher scores always mean worse experience; e.g. worse pain, etc  **Manual**:  Pages 42-45 of the attached manual (ASCQ\_ME Users Scoring Manual) | |
| 1f. ASCQ-Me Pain  Interference Measure | Ascq\_paininter | **108-112** | | 5-item: PROMIS Scale Measure.  **How to score**:  This scale can be measured so long as a min. of 4 items are answered:   1. Sum the response scores for the actual items that were answered 2. Multiply the sum by the total 5 (i.e. the total number of items in our measure) 3. Divide by the number of items that were answered (4 or 5) 4. Use the short form conversion table (4a) to locate the raw score and to obtain a standardized t-score   **Guidelines**:  See attached reference, starting on page 4 | |
| 1g. ASCQ-Me Sleep Measure | Ascq\_sleep | **114- 118** | | 5-item: ASCQ-ME Measure for assessing sleep patterns in the past 7 days.  -Higher scores correlate with worse sleep.  **To Score**:   1. Reverse Code Q115, (i.e. ‘Never’=5) 2. Sum the items to obtain a raw score 3. Use the short form conversion table (4a) to locate the raw score and to obtain a standardized t-score   **Guidelines**:  Please refer to attached guidelines (ASCQ-ME User’s manual; page 42) and Appendix B for short-form conversion (page B-5), See section 1e. | |
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| **2. Stress Measures:** |  |  | |  | |
| 2a. The Cohen Global  Perceived Stress Scale | Cohen\_stress | **341-350** | | 10-item scale (Referred to as PSS10)  -Higher scores indicate more perceived stress  **To Score:**   1. Recode individual item scales from 1-5 to a score of 0-4 2. Reverse code the four positively stated items (q344, q345, q347, q348) so higher scores indicate more perceived stress (i.e. ‘Never’=5) 3. Sum across all scale items   **Manual/Guidelines**:  <http://www.mindgarden.com/docs/PerceivedStressScale.pdf> | |
| 2b. Acute Events-    2b(1). Lifetime (4 items) | Lifetime\_stress | **197- 200** | | 95-item scale. For scoring, please refer to attached guidelines (see section 1c) by Dr. David Williams (Stress/Religiosity Measures) pages 3-16, or see below: | |
| **How to Score**:  4 items: Create a count variable from 0 – 4 for every ‘yes’ response | |
| 2b(2). Past 5 years (11  items), | fiveyear\_stress | **201- 211** | | **How to Score**:  11 items: Create a count variable from 0–11 for every ‘yes’ response | |
| 2b(3). Job Dissatisfaction  (1 item) | Jobdissatis\_stress | **264** | | **How to Score**:  -Create a single item measure  -Reverse code scale, so completely satisfied=5  -Standardize | |
| 2b(4). No control (3 items) | Nocontrol\_stress | **265- 267** | | **How to Score**:  - Sum score of three items,  - Reverse code scale for all 3 items, so strongly agree=4, strongly disagree=1.  -Standardize it. | |
| Nocontrol\_tmp | **Unstandardized, raw score** | | Raw score for 2b(4): higher scores indicate more control. Standardized scores are interpreted as below average or above average. | |
| 2b(5). Job Insecurity 1 (1  item:chances of keeping job) | keepingJob\_stress | **268** | | **How to Score**:  -1 item, standardize | |
| 2b(6). Job Insecurity 2 (1  item: chances of losing job) | LosingJob\_stress | **269** | | **How to Score**:  -1 item, standardize | |
| 2b(7). Work Demands (3  items) | Work\_stress | **270–272** | | **How to Score**:  -Reverse code scale for all 3 items so strongly agree=4  -Sum across all items  -Standardize | |
| Work\_tmp | **Unstandardized, raw score** | | Raw score for 2b(7): Not required for this measure (work\_tmp) | |
| 2b(8). Job-nonJob Conflicts  (2 items) | Jobconflict\_stress | **273–274** | | **How to Score**:  -Sum across all items and standardize | |
| 2b(9). Job-Hazards (3 items) | Jobhazards\_stress | **275–277** | | **How to Score**:  -Sum across all items and standardize | |
| 2b(10). *Global Employment*  *stressors measure (7*  *previous*  *measures, for a total of 14*  *items)* | G\_EmploymentStressors | **264–277** | | **How to Score**:  -Sum the seven prior measures (job  dissatisfaction, no control,  job insecurity1, job insecurity2,  work demands, job-nonjob  conflicts, and job hazard) | |
| 2b(11). Financial Strain (2  items) | Financial\_stress | **278–279** | | **How to Score**:  -Sum across all items and standardize | |
| 2b(12). Total Economic  Problems  (7 items) | Economic\_tmp | **280–286** | | **How to Score**:  7 items: Create a count variable from 0–7 for every ‘yes’ response | |
| 2b(13). *Global Financial*  *Stressors measure (2*  *previous measures, for a*  *total of 9 items)* | G\_Financialstress | **278–286** | | **How to Score**:  -Standardize the total economic problems (economic\_tmp)  -Sum those two prior measures (financial\_stress and economic\_tmp) | |
| 2b(14). Everyday  Discrimination  (5 items) | Discrimination\_stress | **287–291** | | **How to Score**:  -Sum across all items and standardize | |
| 2b(15). Vigilance against  Discrimination (3 items) | Vigilance\_stress | **292–294** | | **How to Score**:  -Sum across all items and standardize | |
| 2b(16). Job Harassment (2  items) | JobHarass\_stress | **295–296** | | **How to Score**:  -Sum both items and standardize | |
| 2b(17). Treated Unfairly  Job (3 items) | JobUnfair\_stress | **297–299** | | **How to Score**:  -Sum across all items and standardize | |
| 2b(18). *Global work*  *discrimination*  *measure (Job harassment*  *and treated unfairly: 5 items*  *total)* | G\_workDiscrim\_stress | **295–299** | | **How to Score**:  -Create a global work discrimination measures by summing job  harassment and treated unfairly on  job) | |
| 2b(19). *Global*  *discrimination*  *measure (everyday*  *discrimination*  *job harassment, treated*  *unfairly:*  *10 items total)* | G\_DailyDiscrim\_stress | **287–291 &**  **295–299** | | **How to Score**:  -Create a global discrimination  measures by summing all prior  items, except vigilance: everyday discrimination, job harassment and  treated unfairly on job | |
| 2b(20). Marital Stress (4  items) | Marital\_stress | **301–304** | | **How to Score**:  -Sum all four items and standardize | |
| 2b(21). Marital Abuse (4  items) | MaritalAbuse\_stress | **305–308** | | **How to Score**:  - Sum across all four items and then standardize  🡪Higher sum scores indicate more marital abuse | |
| 2b(22). *Global Marital*  *problems*  *scale (2 previous*  *measures: 8*  *items total )* | G\_Marital\_stress | **301–308** | | **How to Score**:  -Sum Marital Abuse and Marital Stress (8 items total) | |
| 2b(23). Child-related stress  (3 items) | Child\_stress | **310–312** | | **How to Score**:  -Sum the 3 items and standardize | |
| 2b(24). Total problems for  children (5 items) | ChildProbs\_stress | **313–317, 453** | | **How to Score**:  - Create a count variable from 0–6 for every ‘yes’ response  -Higher count indicates that children are having more current problems (i.e. no job, health problems, relationship prob(s)., etc) | |
| 2b(25). *Global Child Stress*  *Measure (2 prev. items, for*  *a total of 8 items)* | G\_Child\_stress\_tmp | **310–317** | | **How to Score**:  -Based on two prior measures: add standardized child\_stress to childprobs\_stress.  **Note**: It is optional whether we want to standardize childprobs\_stress or not. In our dataset, this measure was standardized. | |
| 2b(26). Friend Criticism (2  items) | Friend\_stress | **318–319** | | **How to Score**:  -Sum both items and standardize | |
| 2b(27).*Global Relationship*  *Stressors scale (marital,*  *child, and friend:19 items)* | G\_RelationshipStress | **301–319** | | **How to Score**:  -Sum global marital, global child, and friend stress (friend\_stress) | |
| 2b(26). Parental stress  (3 items) | Parental\_stress | **320-322** | | **How to Score**:  -Sum all 3 items, standardize | |
| 2b(26). Parental Education  Involvement (2 items) | Parents\_stress | **323–324** | | **How to Score**:  -Sum both items and standardize | |
| 2b(27). Food Insecurity (1  item) | Food\_stress | **325** | | **How to Score**:  -Standardize single item | |
| 2b(28). *Global Early Life*  *Stress Measure (prev. 3*  *measures: 6 items total)* | G\_EarlyLife\_stress | **320–325** | | **How to Score**:  -Sum parental stress, parental education involvement, and food insecurity | |
| 2b(29).Violence (5 items) | Violence\_stress | **326–330** | | **How to Score**:  -Sum all 5 items, standardize  -Higher scores indicate more neighborhood violence | |
| 2b(30). Victimization (4  items) | Victim\_stress | **331–334** | | **How to Score**:  -Create a count variable from 0-4 for every ‘yes’ response  -Higher count indicates more victimization instances (i.e. property damage, attack to self) | |
| 2b(31). Disorder (5 items) | Disorder\_stress | **335–339** | | **How to Score**:  -Sum all 5 items, standardize  -Higher scores indicate more ‘disorder’ (ie graffiti, broken bottles, public fights, etc) | |
| 2b(32). *Global Neighborhood*  *Measure (prev. 3 measures:*  *14 items total)* | G\_Neighborhoodstress | **326-339** | | **How to Score**:  -Sum violence\_stress, victim\_stress, & disorder\_stress | |
|  |  |  | |  | |
| **3. Healthcare & Social Experiences (ASCQ-ME)** |  | | | | |
| 3a. Quality of care for SCD  (7 subsections): |  | | | | |
| 3a(1). Screening  Questions | ---------- | | **120,131, 138,** | | No scale available. |
| 3a(2). Stand-alone  questions: | ---------- | |  | | No individual scale available. These measures are used to study the availability of care for our population. It should be noted that the simplest ‘scoring’ option is to report the frequency distributions of all these individual items.  **Guidelines**:  -Also See Attachment: ‘Scoring Instructions for Scoring Instructions for ASCQ-Me Health Care Experience Measures\_2\_24\_rev.docx’ |
| * How much does this doctor/nurse know how SCD affects you personally? | Standalone\_personal | | **130** | |
| * Does this doctor or nurse treat a lot of patients with sickle cell disease? | Standalone\_population | | **455** | |
| * Do you have a dr/nurse you usually see…. | Standalone\_patient | | **123** | |
| 3a(3).Global Evaluations  of Care (4 items):   1. Patient Satisfaction with scheduled appointments scale 2. Pt. satisfaction with the care they received from their usual provider scale 3. Pt. satisfaction with the care they received in the ER Scale 4. Overall evaluation of care score | Satisfaction\_appointments | | **122** | | **Note on Interpretation/approach**:  Four separate scores are produced for these global measures. Users could report the simple frequency for these measures, but, for making comparisons with results from other CAHPS surveys (the original ASCQ-ME study population), it is recommended that the frequencies be collapsed:  - For the first three global questions, the frequencies in the response categories are collapsed by combining the “Never” and “Sometimes” categories, which simply involves summing the percentage of responses to those two categories.  - The fourth global is an overall evaluation‑of‑care question asking respondents to rate the care they received on a scale from 0 to 10 (Name: CareQual\_Overall) |
| Satisfaction\_care | | **129** | |
| Satisfaction\_ER | | **136** | |
| CareQual\_Overall | | **145** | |
| 3a(4). Individual  Composite Score:  Access to Care (4 Items) | Careaccess | | **121,132, 139, 144** | | 4-items; no individual scale available.  **Note on Interpretation/approach**:  -Three different scales are developed.  -See exhibit 5 for frequency distribution suggestion (page 5). |
| 3a(5). Individual  Composite Score:  Provider Communication  (4 items) | Provider\_communication | | **125,126, 127, 128** | | **4 items total**  **Note on Interpretation/approach**:  No individual scale available. Instead, it looks at the score for the entire population per item (e.g. 11% of our population said that their doctor ‘never’ listens to them):-  1-Collapse the percentage that said ‘never/sometimes’  2- sum across the 4 items to receive composite score for provider communication (see guidelines for examples; Example:  an average of 12% said never sometimes for provider communication composite score; i.e. the doctor explains things to them, listens to them, treats them with courtesy and respect, and spends enough time with them. )  -Can be compared to the CAHPS scores. |
| 3a(6). Individual  Composite Score:  Emergency Department  Care (5 items) | ED\_Care | | **133,134, 135,142**  **143** | | **No individual scale available**.  **Note on Interpretation/approach**:  - Two different scales are used in the 5‑item set—one scale is a four‑response behavioral frequency scale and is used for three of the items in this composite (133-135).  -The other scale, which is used for 2- items (142-143), has five response options indicating the degree to which ED staff was helpful to the patient. See Exhibit 6, page 7 of guidelines. |
| 3a(7). SCD Healthcare  Experience Utilization  Question | Health\_utilization | | **124,137, 141** | | **Note on Interpretation/approach**:  These three items provide information about respondents and do not comment on the quality of care. These items are included to characterize healthcare utilization and can be used for subgroup analysis (e.g. can classify q124 can be heavy vs. light healthcare users) |
| 3a(8). ASCQ-ME ED  Care questions | Ascq\_CareOther | | **140** | | **1 item**  **No individual scale available** |
|  |  | |  | |  |
| 3b. ASCQ-Me Emotional  Distress Scale | Ascq\_emotional | | **147-151** | | 5-item scale  **To Score**:   1. Cannot be scored if any item is missing 2. Sum the response scores for the actual items that were answered 3. Use the short form conversion table (page B-3) to locate the raw score and to obtain a standardized t-score   -Similar to other ASCQ-ME measures, each score is standardized to a mean of 50 w/SD 10, where 50 indicates the health score of the average field test respondent.  **Guidelines**:  Please refer to attached guidelines (ASCQ-ME User’s manual) and Appendix B0. See section 1e. |
| 3c. Beck Depression  Inventory (BDI) | Beck | | **425-445** | | 21 items  **Scoring +Interpretation**:   1. Assign appropriate scores to each response per guidelines; max is 3 points per questions 2. Sum across all items   -Higher scores indicate more clinical depression. A score of 0 – 13 is considered ‘minimal/normal’ depression, and, depending on clinical & study criteria, a cutoff either of >14 or >17 is used for a clinical depression diagnosis.  **Guidelines**:  <http://link.springer.com/article/10.1007/BF01186280#page-1>  Also see: section 1c guidelines starting on page 21. |
| 3d. PANAS Scale | Panas\_positive | | **Q153: Items 1-10** | | 20-Items, 2 scales:  **Scoring and Interpretation**:  -Simply sum the scores for each of the items to obtain these two scales (each scale has 10 items).  -Scores can range from 10 – 50, with higher scores representing higher levels of positive affect and lower scores representing lower levels of negative affect  **Guidelines**:  <http://www.midss.org/content/panas-x-manual-positive-and-negative-affect-schedule> |
| Panas\_negative | | **Q153: Items 11-20** | |
| 3e. Pearlin-Self-Mastery  Scale | Pearlin | | **155-161** | | 7-items.  **How to score**:   1. Can only be coded if all items are answered 2. Reverse code the 5 (negatively-phrased) items: 155 -159), so strongly disagree=4 3. Sum scores for all 7 items   **Note for Interpretation**:  Has a score range of 7 to 28, with higher scores indicating greater levels of mastery over one’s environment (“the extent to which one regards one’s life-chances as being under one’s own control in contrast to being fatalistically ruled”)  **Guidelines**:  <https://www.nlsinfo.org/content/cohorts/nlsy79/topical-guide/attitudes> |
| 3f. Perceived Social  Support/Conflict Scale | Pos\_spouseSup | | **164-169** | | 30 items total, separate scales:  **How to score**:  -Reverse code positive scales: q164-q169, q176-q181, q186-q189, so that “a lot”=4  -An overall or ‘global’ scale is not possible  -Sum and then calculate the mean of the values of the items in each scale.  **Note on interpretation**:  -Positive scales are reverse coded so that high scores reflect higher standing in the scale (e.g. higher scores mean less Neg\_spouseSup)  **Guidelines**:  <https://www.phenxtoolkit.org/index.php?pageLink=browse.protocoldetails&id=180701>  Pages 69 onward: <file:///C:/Users/abdallahke/Downloads/04652-0001-Documentation-scales%20(1).pdf> |
| Neg\_SpouseSup | | **170-175** | |
| PartnerSolidarity | | **164-175** | |
| Pos\_FamilySup | | **176-181** | |
| Neg\_FamilySup | | **182-185** | |
| FamilySolidarity | | **176-179, and 182-185** | |
| Pos\_FriendsSup | | **186-189** | |
| Neg\_FriendsSup | | **190-193** | |
| FriendSolidarity | | **186-193** | |
| **3g. Rosenberg Self-Esteem**  **Scale** | Rosenberg | | **195** | | 10-item scale: **Scoring/Interpretation:**   1. Reverse code (negative) item numbers: 3, 5, 8, 9, 10 so that strongly disagree=4 2. Sum scores for all ten items 3. Higher scores indicate higher self-esteem   **Guidelines**:  <http://fetzer.org/sites/default/files/images/stories/pdf/selfmeasures/Self_Measures_for_Self-Esteem_ROSENBERG_SELF-ESTEEM.pdf> |
|  |  | |  | |  |
| **4. Physical Environment** |  | |  | | No individual scoring, can look at frequency distribution for study cohort |
| 4a. Current Environmental  Tobacco smoke exposure | Tobacco\_exposure | | **250** | | Does anyone who lives w/you smoke? |
| **251** | | If yes, person, relationship, and # of cig. smoked per day inside home |
| **252** | | How many hrs/day can you smell smoke at job/business? |
| 4b. Characteristics of current  residence | Current\_residence | | **233-248** | | No Scoring: asks questions about dwelling, mold (+/-), yrs living in address, heaters, A/C, etc |
|  |  | |  | |  |
| **5. The Religiosity Measures ( 9 scales, see below)** |  | |  | | 14-item scale. Please refer to attached guidelines by Dr. David Williams (Stress/Religiosity Measures). See section 1c, starting on page 17, or see below |
| 5a. Religious Attendance  (1- item) | Religious\_attendance | | **254** | | **How to Score**:  -single item, reverse code (so that “Never”=1,  “Several Times/week”=5),  - standardize  -Also create a categorical variable:  collapse categories 1-2 vs 3-4  vs 5-6 vs 7 (Variable |
| 5b. Positive Congregational  Support (2 items) | Pstve\_congsupprt | | **255–256** | | **How to score**:  -Reverse code 255, 256 (so that ‘a great deal’=5), sum,  -Standardize  --Higher scores indicate more positive support |
| 5c. Negative Congregational  Support (2 items) | Ngtve\_congsupprt | | **257- 258** | | **How to score**:  -Reverse code 257-258,  (so that “Very Often”=5) --Sum, standardize  -Higher scores indicate more negative support |
| 5d. Spirituality  (1-item) | Spirituality | | **259** | | **How to score**:  -Reverse code (so that “Very  spiritual=4”)  -Standardize single item measure |
| 5e. Intrinsic Religiosity  (1- item) | Intrinsic\_religiosity | | **260** | | **How to score**:  Intrinsic Religiosity: reverse code (so that ‘a great deal=5)  -Standardize single item measure |
| *5f. Global Religious/Spiritual*  *Salience Scale (prev. 2*  *measures: 2 items total)* | Global\_religious | | **259-260** | | **How to score**:  Create a global Religious/Spiritual  salience scale by summing  259, 260 |
| 5g. Positive Religious Coping  (2 items) | Pstve\_religiouscoping | | **261 (first 2 sub-questions/items)** | | **How to score**;  -Reverse code (so that  ‘a great deal=6),  -sum and standardize (1) and (2) |
| 5h. Negative Religious Coping  (2 items) | Ngtve\_religouscoping | | **261 (last 2 sub-questions/items)** | | **How to score**:  -Reverse code (so that  ‘a great deal=6),  -Sum all items  -Standardize items (3) and (4) |
| 5i. Religious Meaning  (4 items) | Religion\_meaning | | **262 (4 sub-questions/items)** | | **How to score**:  Religious Meaning:  reverse code (1) and (3) (so that  ‘Strongly Agree’=4),  -Sum  -Standardize all 4 items |
|  |  | |  | |  |
| **6. Centrality and Regard Subscales of the MIBI Scale (Racial Identity)**  **(**MULTIDIMENSIONAL INVENTORY OF BLACK IDENTITY (MIBI)) | Centrality\_racial\_identity | | **352-359** | | 8-items scale:  **How to score**:   1. Reverse score items: 352, 355, 359 by subtracting 8 from each individuals' score on the item. So that Strongly disagree=7 2. Next, sum the items and average the scores for all of the items in this scale   **Note on Interpretation**:  The centrality dimension of racial identity refers to the extent to which a person normatively defines his/herself with regard to race.  It is an indicator of whether race is a core part of an individual's self-concept.  Implicit in the conceptualization of centrality is a hierarchical ranking of different identities with regard to their proximity to the individual's core definition of self. Higher scores indicate more of this dimension.  **Guidelines**:  <http://sitemaker.umich.edu/aaril/files/mibiscaleandscoring.pdf> |
|  |  | |  | |  |
| **7. Brief Resilience Scale** | BRS\_Resilience | | **361-366** | | 6-item scale that measures the ability to bounce back or recover from stress. Higher scores indicate more resilience or ability to “bounce back”  **How to score**:   1. The BRS is scored by reverse coding items: 362, 364, 366, so that strongly disagree=5 2. Find the mean of the six items   **Scoring guidelines**, page 195: <http://homepages.uwp.edu/crooker/745-resile/articles/smith-etal-2008-brs-indiv.pdf> |
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| **8. Self-Compassion Scale (SCS)** | Self\_Kindness | | **393, 386, 379, 390, 372** | | 26-item scale: breaks down into 6 sub-scales and then one overall scale (variable name: self\_compassion; see below)  **How to score**:   1. Reverse code responses to these negatively worded items: 368, 369, 371, 373, 375, 378, 380, 383, 385, 387, 388, 391, 392, so that ‘almost never=6’ 2. Calculate the mean for these subset 6 items: self\_kindess through over\_identification 3. Sum the means of those 6 subsets to create a total self-compassion score comprising the self-kindness, self-judgment, humanity, mindfulness, isolation, and over-identification subscales.   **Interpretation**:  -Overall self-compassion score: higher scores are associated with more positive standing  **Scoring Guidelines,** pages 231-233:  <http://self-compassion.org/UTserver/pubs/empirical.article.pdf> |
| Self\_judgment | | **383, 375, 388, 368, 378** | |
| Common\_humanity | | **377, 382, 374, 370** | |
| Isolation\_SCS | | **392, 371, 380, 385** | |
| Mindfulness\_SCS | | **379, 389, 381, 384,** | |
| Over\_Identification | | **387, 369, 391, 373** | |
| Self\_compassion | | **368-393** | |
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| **9. Social Desirability Scale (SDS)** | Social\_desirability | | **395-399** | | 5-item scale.  **How to score**:   1. The scale ranges from 0 – 5 2. Scores of 1 are assigned to extreme values and 0 assigned to all other values 3. Extreme values per question: Item 395= response 1 (def. true), 396= response 5 (def. false), 397= response 5 (def. false), 398= response 5 (def. false), 399= response 1 (def. true) 4. Sum the total score for all 5 items 5. No need to perform Linear transformation   **Guidelines**:  Hays, et al. page 633: <http://epm.sagepub.com/content/49/3/629.full.pdf+html>  RAND:  <http://www.rand.org/content/dam/rand/www/external/health/surveys_tools/sdrs/sdrs5_survey.pdf> |
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| **10. John Henryism Scale** | Henryism | | **401-412** | | 12-items sum score (ranges from 12 to 60):  **How to score**:   1. Assign the following scores/points to each response: 1=’completely false’, 2=’somewhat false’, 4=’somewhat true’, 5=’completely true’ 2. A ‘don’t know’ response is to be omitted 3. Sum the scores of the 12 questions (range= 12 to 60) 4. If one of the twelve answers is missing, a summary score can be computed as the average of the remaining eleven and multiplied by 12 5. Not more than 1 out of 12 answers can be missing   **Guidelines**:  with higher scores indicating higher coping, page 6: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3109756/> (section 2.3) |
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| **11. Health Related Behaviors** |  | |  | |  |
| 11a. Alcohol Lifetime Use | Etoh\_lifetime | | **23** | | Yes/No response, so no score. |
| 11b. Alcohol 30-day quantity  and frequency | Etoh\_30days | | **24-25** | | No score.  Phenx Tool: <https://www.phenxtoolkit.org/index.php?pageLink=browse.protocoldetails&id=30301> |
| 11c. Tobacco Smoking status  11d. Tobacco 30-day quantity  and Frequency | Smoker\_status | | **26** | | 🡪create a new category to determine smoking status using the following conditioning:   * If response to Q26 is ‘No’ then smoker\_status= 0 (Never a smoker) * If response to Q26 is ‘yes’ and q27 is ‘every day’ then smoker\_status=1 (current every day smoker) * If response to q26 is ‘yes’ and q27 is ‘some days’ then smoker\_status= 2 (‘Current some days smoker’) * If response to q26 is ‘yes’ and q27 is ‘not at all’ then smoker\_status=3 (‘Former smoker’) * If q26 is ‘yes’ and q27 is ‘some days’ and q28 is ‘yes’ then smoker\_status=4 (‘smoked everyday in the past’) * If q26 is ‘yes’ and q27 is ‘not at all’ and q28 is ‘yes’ then smoker\_status=5 (‘Past everyday smoker’)   **Guidelines**:  See phenX toolkit: (<https://www.phenxtoolkit.org/index.php?pageLink=browse.protocoldetails&id=30602> ) |
| Tobacco\_30days | | **27-31** | |
| 11e. History of being breast-  fed | Breast\_Fed | | **34** | | Yes/No responses; No score. |
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| **12. Medical Mistrust Index** | Mistrust | | **456 (after Q145)** | | **-**7-items (ranges from 1 to 4).  **How to score**:   1. Sum the scores for all 7 items 2. Find the mean   **Interpretation**:  -Overall MMI Score: Higher scores indicate greater mistrust.  **Scoring Guidelines,** page 2096:  <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2796316/?report=reader> |
| **13. Perceived Stressful Discrimination**  **13a. Racisim or discrimination from non-AAs**  **13b. Racisim or discrimination from Other AAs** |  | | **457-470**  **457-463**  **464-470** | | **-**14-item |
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