***A*dult *S*ickle *C*ell *Q*uality of Life *Me*asurement Information System**

ASCQ-Me®
User's Manual

ASCQ-ME USER'S MANUAL

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CHAPTER 1: OVERVIEW OF ASCQ-ME

Background

The Need for ASCQ-Me

The life expectancy of individuals who have sickle cell disease (SCD) has steadily improved over the last several decades. Due to improvements in therapy, SCD has become a chronic health condition that many people manage into old age. Because SCD has evolved in this way, we have a better grasp of acute treatment needs than we have of the long-term needs of adults who live with SCD. In response to these gaps in our understanding, the National Heart, Lung, and Blood Institute (NHLBI) began a series of conferences and workshops in 2002 to determine ways to improve treatment for adults who have SCD. These meetings concluded that there was a need to develop a way to assess the quality of life of adults who have SCD to assess the impact of SCD on the lives and experiences of affected adults. The measurement system would augment data from randomized clinical trials of treatments for SCD, would be used to improve the delivery of health care to adults who have SCD, and would inform programs directed toward improving quality of life for adults who have SCD. NHLBI contracted with the American Institutes for Research (AIR) to develop the system, which we call the Adult Sickle Cell Quality of Life Measurement Information System (ASCQ-Me).

Comprehensive, Multi-Method Approach

When our team began the development of ASCQ-Me, no disease-specific health-related quality of life (HRQOL) instrument for SCD existed, so our formative research was inductive. We conducted a comprehensive literature review of the quality of life and psychosocial literature on adults who have SCD. We integrated the results of the literature review with information from earlier NHLBI working groups to develop a preliminary conceptual model of the impact of SCD on adults. We next conducted a series of structured individual and group interviews with adults who have SCD and their health care providers. The in-depth interviews and focus groups were used to identify the HRQOL domains that are most salient to persons who have SCD and their providers, as well as prioritize potential domains reported by participants that are derived from the NHLBI working groups and the literature review. We also solicited input on preferences for the modalities for administering ASCQ-Me, including paper and pencil, computer, and telephone. We conducted critical incident interviews (CII) with adults who have SCD, and their providers, which generated 1,213 concrete examples of how SCD affected adult lives. We then developed items based on the incidents. For example, the item "*In the past 7 days, how often were your joints very stiff when you woke up?"* and its response choices from "*Never"* to "*Always"* were derived from the critical incident: *"I wake up in the morning and feel like I'm 80 years old. I am* ***stiff.*** *My* ***back and joints*** *will* ***feel out of place.*** *I have to spend a lot* ***more time in the morning just to get started.***" Selected items underwent cognitive testing, with the goal of determining if the items were understandable and asking what they were intended to ask. Items were rewritten as needed, based on the results of the cognitive testing. Initially, 830 items had been drafted based on the incidents, but items were deleted before the field test based on redundancy, qualitative item review, and cognitive testing results.

The ASCQ-Me field test included more than 230 items and was conducted at seven locations, including community-based academic and clinical sites. Five hundred sixty-one adults were

enrolled in the field test; 63.6 percent (n = 357) were women. The median age of field test participants was 18–34 years, and 64.2 percent (n = 360) were diagnosed with SCD-SS (the homozygous form in which both hemoglobin genes carry the sickle cell mutation).

ASCQ-Me and PROMIS

Our approach to the development of ASCQ-Me used a wide range of qualitative and quantitative research methods similar to those used for the Patient-Reported Outcomes Measurement Information System (PROMIS), a National Institutes of Health (NIH) Common Fund initiative. PROMIS is a network of NIH-funded primary research sites and coordinating centers working collaboratively across disciplines to develop reliable and valid measures of patient-reported outcomes. PROMIS measures have been under development since 2004, and include questions for adults, children, the general population, and individuals who have disabilities and chronic conditions. Like PROMIS, ASCQ-Me uses adaptive computer technology and item response theory models to make the development of standardized patient reported outcomes possible, while reducing respondent burden.

We developed ASCQ-Me to be a stand-alone system that, nevertheless, would be complementary to PROMIS. The ASCQ-Me team had access to PROMIS methods, investigators, and technologies throughout the course of the ASCQ-Me development, and four PROMIS item banks were included in the ASCQ-Me field test, covering pain (interference and quality), physical functioning, and fatigue. Combining ASCQ-Me with PROMIS allows comparisons of the burden of SCD relative to that of other chronic diseases, for which PROMIS measures are used. ASCQ-Me augments PROMIS by providing measurements specific to SCD. For example, while PROMIS has a pain item bank, few individuals who have chronic disease suffer the degree, sudden onset, and specific locations of pain characteristic of SCD. We developed Pain Episode items that could either augment measures in the PROMIS pain item bank or stand alone. The pain of adults who have SCD can be compared to that of adults who have other chronic diseases (e.g., arthritis) on the PROMIS measures. But the unique features of SCD pain that may respond to therapy can be described, with greater sensitivity, using the ASCQ-Me questions.

ASCQ-Me Measures

The total ASCQ-Me measure set (see Exhibit 1–1) consists of both computer-adaptive and static (i.e., fixed) scales to target the topics in black bold font below. The concepts behind the ASCQ-Me measures were based on a conceptual framework of how SCD affects adult lives which, in turn, was based on a comprehensive program of formative research which is described on this website and in a publication in the *Clinical Journal of Pain*.[1] The portion of this conceptual framework that forms the basis of the current version of the ASCQ-Me HealthMeasures is indicated by the bold black type in Exhibit 1–1 below. The topics in green type are included in PROMIS. The topics in orange type require future development.

The health domains assessed by adaptive scales include:

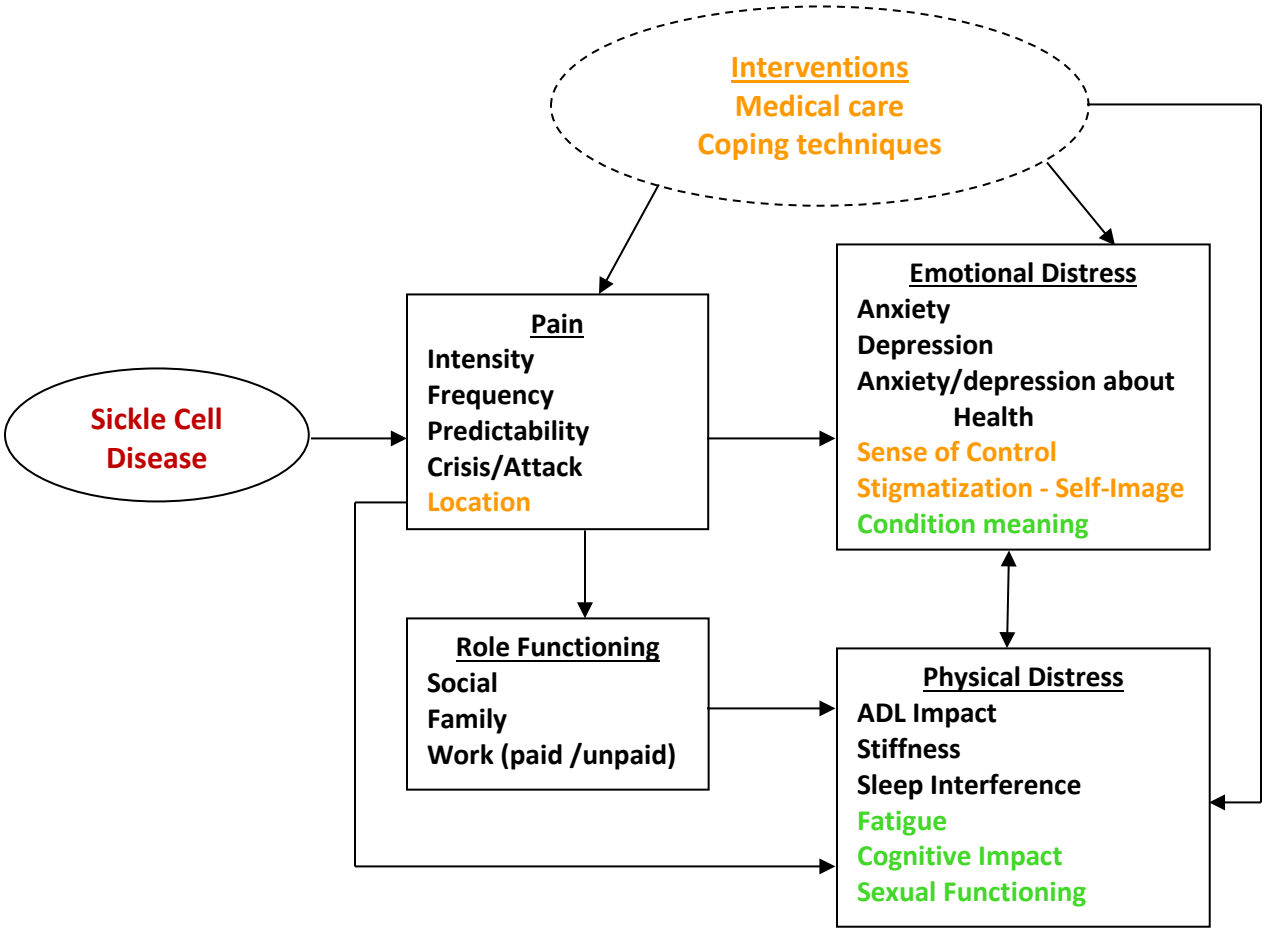
[1] Treadwell, M. J., Hassell, K., Levine, R., & Keller, S. (2014). Adult Sickle Cell Quality-of-Life Measurement Information System (ASCQ-Me): Conceptual model based on review of the literature and formative research. *The Clinical journal of pain, 30*(10), 902-914.

- Emotional Impact
- Pain Impact
- Sleep Impact
- Social Functioning Impact
- Stiffness Impact

The domains assessed by fixed scales include:

- Pain Episodes
- SCD Medical History Checklist

Exhibit 1–1. ASCQ-Me Measure Set and Potential Relationships among Measures



ASCQ-Me is suitable for use in research that includes cross-sectional comparisons of adults who have different levels of severity, or in comparison with the health burden, of different diseases; cross-sectional evaluation of effectiveness of a drug in a random sample of patients who have

been taking the drug; evaluation of change during a randomized controlled trial; and observational study of change due to a therapeutic intervention.

The remainder of this users' manual provides a set of options and instructions to help users administer ASCQ-Me. As a user, you may want to first select an appropriate administration modality for your own study. In Chapters 2 and 3, we describe the administration process by modality; and in Chapter 4, we describe how ASCQ-Me measures are scored across different modalities.

Selecting Modalities

Portions of ASCQ-Me are available in a choice of two modalities: traditional paper and pencil, and an electronic version that can implement Computer Adaptive Testing (CAT) technology[2]. You should choose the format or combination of formats that best fit your needs. Exhibit 1–2 compares the two versions on characteristics that are important to consider when choosing a format.

Please note that ASCQ-Me questions have not been tested in an interviewer-administered mode. That means that we do not know what would be the influence on the responses of administering the questions over the phone or in person. Previous research with other patient-reported outcome measures has shown that respondents answer questions about health differently when another person asks them the questions than when they answer in private. Thus, until research is conducted to evaluate an interviewer-administered mode, we recommend that you use either the paper and pencil administration or the electronic administration mode.

Survey Development

Detailed instructions for creating an ASCQ-Me survey are presented for each modality found later in this manual. Some general instructions are presented here.

Sometimes you may want to add your own questions in the data collection. It is recommended that you place any additional questions at the end of all of the ASCQ-Me questions. Research shows that the order of question presentation can have an influence on how respondents answer. Adding original questions at the end of your survey will help avoid any such influences on the ASCQ-Me question responses.

Exhibit 1–2. Important Features of the Two ASCQ-Me Formats

	ASCQ-Me Modes	
	Paper & Pencil	Electronic
Participants can respond in private	✓	✓
Participants can respond at their convenience	✓	✓
Research indicates no bias due to mode of administration	✓	✓
Includes SCD Medical History Checklist	✓	✓
Includes SCD Pain Episode measure	✓	✓

[2] Please see Chapter 3 for more information about CAT.

	ASCQ-Me Modes	
	Paper & Pencil	Electronic
Provides immediate data capture		✓
Built-in data quality features		✓
Presents one question at a time		✓
Built-in respondent tutorial		✓
Built-in features for customization		✓
Automatic data file creation		✓
Requires 8th grade literacy	✓	✓[a]
Includes Emotional Impact SF	✓	✓
Includes Pain Impact SF	✓	✓
Includes Sleep Impact SF	✓	✓
Includes Social Functioning Impact SF	✓	✓
Includes Stiffness Impact SF	✓	✓
Does not require vision		✓[a]
Requires ability to write	✓	
Requires data entry	✓	
No special equipment required	✓	
Allows respondents to view all questions without having to answer them	✓	
Includes Emotional Impact CAT		✓
Includes Pain Impact CAT		✓
Includes Sleep Impact CAT		✓
Includes Social Functioning Impact CAT		✓
Includes Stiffness Impact CAT		✓
Requires ability to use a computer and computer mouse		✓
Calculates scores automatically		✓

[a]The electronic ASCQ-Me mode can have the option for audio administration of questions.

Protected Health Information

The Health Insurance Portability and Accountability Act (HIPAA), as well as the human subjects' requirements of IRBs require protection of health information about individual patients. To facilitate compliance, ASCQ-Me was developed for anonymous collection of data. Therefore, this manual will not cover procedures for protecting health information. Please consult your IRB for guidance on HIPAA and human subjects' requirements and your role as a researcher or clinician in protecting health information.

ASCQ-Me Copyright and Terms of Use

ASCQ-Me is a patient-centered data collection tool that is made available for clinical study of adults who have sickle cell disease (SCD) for understanding: (1) the impact of SCD, and (2) interventions to improve the treatment of adults with SCD on their functioning and wellbeing. The NHLBI provided the AIR with initial funding to develop the first ASCQ-Me prototype and AIR continued to invest in further development of ASCQ-Me after NHLBI funding concluded in 2010. The support of ASCQ-Me is consistent with AIR's mission to: "...conduct and apply the best behavioral and social science research and evaluation towards improving people's lives, with a special emphasis on the disadvantaged." AIR owns the copyright to ASCQ-Me. The copyright is intended to: (1) protect the integrity of the measure, (2) ensure that the AIR researchers most

experienced with ASCQ-Me will continue to assist users, and (3) support future improvements to the measure. Access to ASCQ-Me is not restricted by the copyright.

CHAPTER 2: ASCQ-ME PAPER-AND-PENCIL INTERVIEW (PAPI) ASCQ-ME

Paper Survey Development

ASCQ-Me allows you to select from the currently available fixed-length/fixed-order question sets and, also, to add your own questions. When fixed-length/fixed-order questions are used, a person answers a set of questions that are asked in a specified order. The person's responses to all of these questions are used to produce a score.

PDF versions of all available fixed-length/fixed-order question sets can be obtained at http://www.healthmeasures.net/search-view-measures. Exhibit 2–1 summarizes the measures currently available in PDF format, and an example of the paper questionnaire is shown in Exhibit 2–2.

Exhibit 2–1. ASCQ-Me Paper and Pencil Questionnaires

ASCQ-Me Question Sets	Number of Items	Type of Administration
Emotional Impact	5	Fixed length/order
Social Functioning Impact	5	Fixed length/order
Pain Impact	5	Fixed length/order
Stiffness Impact	5	Fixed length/order
Sleep Impact	5	Fixed length/order
SCD-MHC[a]	9	Fixed length/order
Pain Episodes	5	Fixed length/order

[a]Sickle Cell Disease Medical History Checklist

You have the option to choose the order in which the question ***sets*** will be administered, but not the order of ***each item*** within a set. When adding your own questions, you are strongly urged to add any additional questions ***at the end*** of the ASCQ-Me survey, thus ensuring that all ASCQ-Me data are collected in a comparable fashion. Asking questions prior to the ASCQ-Me items might influence a person's responses to the ASCQ-Me items and could compromise the comparability of your data.

Assemble the Survey

Which Question Sets?

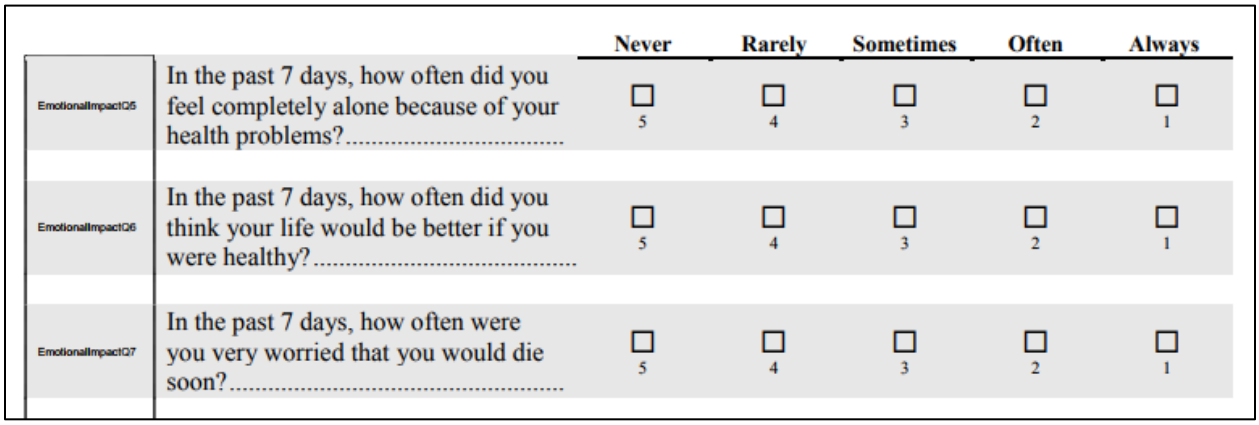
It is recommended that all respondents be given the age and gender questions, as well as the Sickle Cell Disease Medical History Checklist (SCD-MHC). This will allow you to describe the group of respondents and identify subgroups of respondents for analysis. The use of additional question sets will vary according to the information needs of your study.

Question Set Order

If a number of question sets are being assembled into a packet or a booklet, age, gender, and SCD-MHC question sets should be presented at the end of the questionnaire, in this order. Leaving until the end the questions that characterize the respondents will reduce the effect of respondent sensitivities on the quality of responses and item response rates for those question sets that assess the experience of SCD symptomatology. When respondents are asked their age

and gender, or other sociodemographic information, they may feel less anonymous and their responses to subsequent questions can be inhibited if they feel less anonymous.

Exhibit 2–2. Sample Paper Questionnaire



		Never	Rarely	Sometimes	Often	Always
EmotionalImpactQ5	In the past 7 days, how often did you feel completely alone because of your health problems?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
EmotionalImpactQ6	In the past 7 days, how often did you think your life would be better if you were healthy?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
EmotionalImpactQ7	In the past 7 days, how often were you very worried that you would die soon?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1

Answering questions about disease severity can bias respondents' answers to subsequent health questions to be more consistent with their reported severity. The order of these three question sets relative to one another should be age/gender first and SCD-MHC second in keeping with the increasing potential threat to data quality that each represents.

Choose a Data Collection Location

Paper and Pencil Interviewing

Paper and Pencil Interviewing (PAPI) data can be collected through the mail or at the site of care, and is usually self-administered by the respondent. Once a method of distributing the survey is chosen, it should be used for every study participant. If ASCQ-Me is used in a longitudinal study in which participants complete the survey at different times over the course of the study, the same method of administering the survey should be used for each data collection.

If You Collect Data at a Clinic or Other Site of Care

Most clinical research data are collected at the location where care is delivered, so patient questionnaires are often administered in the clinic. Study site coordinators can be instructed in how to incorporate ASCQ-Me into the rest of the data that are collected for the study. Participants should complete the ASCQ-Me question sets before they have any other medical tests or procedures, and before they see their provider, so that their answers are not biased in the direction of the other tests or by information about their condition communicated by staff. In addition, it is important that respondents answer the questions without being helped or influenced by friends or family who may accompany them. The site coordinator, likewise, should not say anything that would influence the participant to choose a particular answer. This is important no matter which mode of data collection is used.

If You Collect Data through the Mail

For studies in which travel to the clinic is not required or practical, participants may respond to the survey at home and mail it back to the clinic or to a data coordinating center. In that event, procedures should be set up to make it easy for the participant to return the survey.

Mailed envelope. The study materials, including a cover letter, paper copies of the survey, and self-addressed, stamped, return envelopes should be mailed in an envelope that would not be mistaken for junk mail. The envelope should be marked "forwarding and address correction" in case the address on record is incorrect. First class postage—preferably stamps rather than metered postage—should be used to distinguish the envelope from junk mail. The included cover letter should be short, easy to read (large type with generous amounts of white space), compelling, and printed on letterhead. It should come from an authoritative person, such as the study's principal investigator or someone in a senior administrative position from the funding agency or sponsor. It can be valuable to include on the cover letter a list of respected local or national organizations, such as support or advocacy groups that have agreed to endorse the research. If the letterhead is from a clinic or place of care, the text should include a statement such as: ". . . while your participation is important to the results of this (research or survey), your access to care and the quality of your care will not be affected in any way if you cannot or do not wish to participate." The letter should include a toll-free number to call and/or a URL where the recipient can receive more information about the study or survey.

800-Number and FAQs

A study 800-number staffed with trained research team members is a good way to encourage participants to respond by providing them with a way to get quick answers to their questions. The staff members who answer the phone should keep a log of questions and answers, as these could be used to improve the study. As questions accumulate, a list of frequently asked questions (FAQs) and answers should be drafted to help standardize answers among staff representatives and make it easier to train new representatives.

Follow-up

The Consumer Assessments of Healthcare Providers and Systems (CAHPS) (www.cahps.ahrq.gov) has successfully increased participation in their surveys by using this follow-up protocol:

1. **10 days after the initial mailing:** Send a letter reminder to nonrespondents thanking those who have responded and reminding or encouraging those who have not responded to please do so.
2. **30 days after the initial mailing:** Send a second survey packet containing all the materials in the original mailing with the exception of the original cover letter. The original cover letter should be replaced with a follow-up cover letter that thanks participants who have mailed back their completed questionnaires, and informs those who have not that there is still time to respond and that responding is very important.

Examples of the cover letter and reminder letter are shown in Exhibits 2–3 and 2–4, respectively.

Exhibit 2–3. ASCQ-Me Questionnaire Cover Letter

December 13, 2015

John Doe
56 Golden Pond Lane
Mayberry, NC 27030

Dear Mr. Doe,

We at Chapel Hill Sickle Cell Disease Clinic need your help in answering questions that will help us to see how sickle cell disease and treatments are affecting your life. We hope that you will take a few minutes to complete the enclosed questionnaire.

The information that you provide will be kept completely private and confidential and your answers will never be matched with your name.

We hope you will take this chance to tell us about your experiences with your sickle cell disease. Please return the completed survey in the enclosed postage-paid envelope by December 31, 2015. Whether you choose to participate or not, your sickle cell care at Chapel Hill Sickle Cell Disease Clinic will not be affected.

If you have any questions about this survey, please call Dr. Smith at (800) 303-1575. All calls to this number are toll free. Thank you for taking the time to complete the questionnaire

Sincerely,

Dr. John Smith
Chapel Hill Sickle Cell Disease Clinic

Exhibit 2–4. ASCQ-Me Questionnaire Reminder Letter

January 5, 2016

John Doe
56 Golden Pond Lane
Mayberry, NC 27030

Dear Mr. Doe,

Recently we sent you a questionnaire asking about your experiences with your sickle cell disease. It should not take you long to complete and your answers will help us see how sickle cell disease and treatments are affecting your life.

When you have completed the questionnaire, please mail it back in the postage-paid envelope that came with it. If you have already sent back a completed questionnaire, thank you!

If you did not get the questionnaire or have lost it, please call Dr. John Smith toll-free at (800) 303-1575, and we'll send you another. You can also call that number if you have any questions. Thank you!

Sincerely,
Chapel Hill Sickle Cell Clinic

Determine Which Observations Are Complete

During data collection, respondents receive, complete, and return surveys in the mail or respond to the survey in the clinic. Often, respondents will answer most of the questions but not all of them. In this case, it is necessary to determine if the questionnaire can be used for analysis. The criteria for making this determination are based on the total number of questions that are completed and the completion of certain required "key" questions. Exhibit 2–5 lists the questions on each ASCQ-Me scale that must be answered in order to compute a total score.

Exhibit 2–5. Questions Which Must Be Answered to Compute Scores for Each Domain

ASCQ-Me Paper and Pencil Interview (PAPI) Question Sets	Total # of Items	Required for Complete
Emotional Impact	5	4
Social Functioning Impact	5	4
Pain Impact	5	4
Sleep Impact	5	4
Stiffness Impact	5	4
Pain Episode Frequency and Severity	5	All
SCD-MHC	9	All

Data Tracking Procedures

You will need a data tracking procedure to populate interim reports regarding the progress of the data collection, and to know when you can stop data collection efforts. To do so, assign a unique ID number to each potential respondent, and record that number next to the personal identifiers and contact information for that respondent on a list that **does not include the respondent's answers to the questions.** The completed survey should contain no identifying information about the respondent except the ID number. The document linking the ID number to the respondent's identifying information should be stored in a separate and secure place that is not located where the completed question sets are stored or where the resulting ASCQ-Me data set is stored. This approach is required to protect the confidentiality of research participants so that they feel free to provide confidential answers to the questions.

In addition to the linkage list and the folder with completed questionnaires, you will need a database to track the status of each respondent's survey completion. This tracking document should include the respondent's ID number and the status of the respondent's data using predetermined status codes. At a minimum, the code should indicate whether the response is pending (P), received but incomplete (I), or received and complete (C); and mailing dates for the initial survey packet, reminder letter (if necessary), and second survey packet (if necessary). The tracking document should also include fields to record when the next mailing is scheduled to take place, and when the completed (or incomplete) questionnaires were received.

The tracking information can be linked to the respondent's contact information and recorded on the same document to easily initiate follow-up mailings. However, if you or your IRB wants to maintain a higher level of security, you should store patient identifying information (e.g., contact information) elsewhere in a separate document.

It is preferable to record the linkage and tracking information using electronic database software, such as MS Excel, MS Access, or their equivalents. It is essential that the computer be backed up at regular intervals, preferably daily. However, your tracking records can also be maintained as paper records, which might look something like Exhibit 2–6, if the tracking and contact information are kept in the same document.

Exhibit 2–6. Example Paper Tracking Document

ID	1st Packet	Letter	2nd Packet	Contact	Status Assigned[a]	Status Date
001	09-12-15	09-22-15	10-13-15	Mr. John Doe; 56 Golden Pond Lane, Mayberry, NC 27030; 919-803-4356	C	10-14-15
002	09-12-15	N/A	N/A	Ms. Jane Doe; 100 Golden Pd Ave, Charlotte, NC 27600; 919-303-0430	I	09-16-15
003	09-12-15	09-22-15	10-13-15	Mr. Michael Smith; 121 Golden Pd Ave, Charlotte, NC 27600; 919-303-1575	P	—

[a] C = complete; I = incomplete; P = pending

Paper records must be kept in a locked file cabinet in a locked room in secured premises or meet other standards established by your IRB.

Create a Data File for Analysis

For completed paper questionnaires, you will need to carry out several tasks to prepare the data for analysis. These steps include identifying and excluding ineligible responses, coding, data entry, and data cleaning. Each questionnaire must be reviewed to see whether the responses are legible and whether any responses need to be recoded. After this review is completed, the questionnaire data will be entered into an electronic spreadsheet or text file. The rows of this file should be defined by the respondent ID and the columns by a unique question label or number, as illustrated in Exhibit 2–7. The cells are populated with a numeric value that corresponds to the answer that the respondent selected. So, respondent "001" chose the response to Question 1 (Q1) which has a code of 3.

Exhibit 2–7. Example Data File Layout

ID	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Etc.
001	3	3	4	2	2	5	3	3	3	1	4	4	4	
002	1	1	2	1	1	2	2	5	5	4	3	3	2	
003	3	3	3	5	3	3	3	3	3	5	3	3	3	
004	5	5	5	4	4	5	4	5	4	4	4	5	5	
005	4	4	3	4	3	3	2	3	3	4	3	3	3	
Etc.														

This data file format is easily read by most statistical software packages. To ensure accuracy of data entry, the questionnaire data should be entered independently by two different people and the results compared. This is called "100 percent double keying" and verifying. If double entry is not practical, a subset of the entered data should be compared to the original paper copies to check for accuracy.

Clean the Data

Incorrect Data

Data that are manually entered will likely contain some mistakes, especially if you do not have the resources to have the data double keyed. Once the data file is complete, you should determine the frequencies for each question value. This will identify values that are out of range (i.e., not one of the possible response values). A review of the original paper copy of the questionnaire will be required to determine the correct value. If the correct value cannot be determined, it should be considered as missing. Any changes to the data should be documented, and a copy of the original data file (i.e., the file before any changes are made) should be saved in case the changes themselves are incorrect or otherwise problematic and need to be reversed at some point.

Duplicate Data

The frequency of the respondent ID will indicate whether the appropriate number of observations for each respondent is included in the data file. If data were collected just once, the frequency should be one for each ID. In the case of multiple entries for an ID, a determination must be made about the source of the double entry, and one of the records should be deleted. On rare occasions, a respondent will be given two copies of the same questionnaire and both will be

returned by mail in different envelopes. In that case, the second questionnaire should be discarded. This is because the respondent's first questionnaire is answered under conditions most similar to those under which the other data are collected. That is, for those respondents who only have one copy, that copy is the first questionnaire that they answer.

CHAPTER 3: ASCQ-ME ELECTRONIC ADMINISTRATION

Electronic administration of ASCQ-Me is required in order to use the computer-adaptive testing (CAT)[3] software, also called computer-adaptive health assessment. But ASCQ-Me short forms also can be administered electronically. Thus, the electronic administration platform allows you to choose either the short forms or the adaptive assessments. When adaptive measures are used, the computer asks the respondent a question, and the score calculated on the basis of that response, determines which next question needs to be asked in order to provide a more precise score for the individual on that measure. When fixed-length/fixed-order questions are used, a person answers a set of questions that are asked in a specified order. The person's responses to all of those questions are used to produce a score for that person.

Exhibit 3–1 outlines the available measures and their formats.

Exhibit 3–1. ASCQ-Me Assessments and Formats

ASCQ-Me Question Sets		Number of Items	Type of Administration
1	Emotional Impact CAT	20	Adaptive
	Emotional Impact SF	5	Fixed length/order
2	Social Functioning Impact CAT	17	Adaptive
	Social Functioning Impact SF	5	Fixed length/order
3	Pain Impact CAT	13	Adaptive
	Pain Impact SF	5	Fixed length/order
4	Stiffness Impact CAT	15	Adaptive
	Stiffness Impact SF	5	Fixed length/order
5	Sleep Impact CAT	12	Adaptive
	Sleep Impact SF	5	Fixed length/order
6	SCD-MHC	9	Fixed length/order
7	Pain Episode Frequency and Severity	5	Fixed length/order

For most systems which administer ASCQ-Me electronically, scores are recorded in an Excel/CSV database that can be imported into SAS or translated into another format suitable for analysis. The spreadsheet is set up so that the row headings are populated with the respondent IDs and the column headings are populated with the variable labels (corresponding to each question in the item bank or short form). The cells are populated with the item or total-score values as appropriate.

[3] This technology originated in education so it refers to "testing". A more suitable term for PRO's is computer adaptive health assessment. Still the acronym for computer adaptive testing -- or CAT – is widely used in health services and clinical research and clinical practice to refer to computer adaptive health assessments.

CHAPTER 4: SCORING ASCQ-ME

This chapter describes how the answers that people choose in response to the ASCQ-Me questions are assigned a value and how these values are combined to create scores. We first describe how this is done for the ASCQ-Me measures that are derived from item banks. These are the adaptive and short-form measures for the five concepts: Emotional Impact, Social Functioning Impact, Pain Impact, Sleep Impact, and Stiffness Impact. Subsequently we describe how each of the remaining question sets is scored; that is, the SCD Medical History Checklist and the Pain Episodes measure.

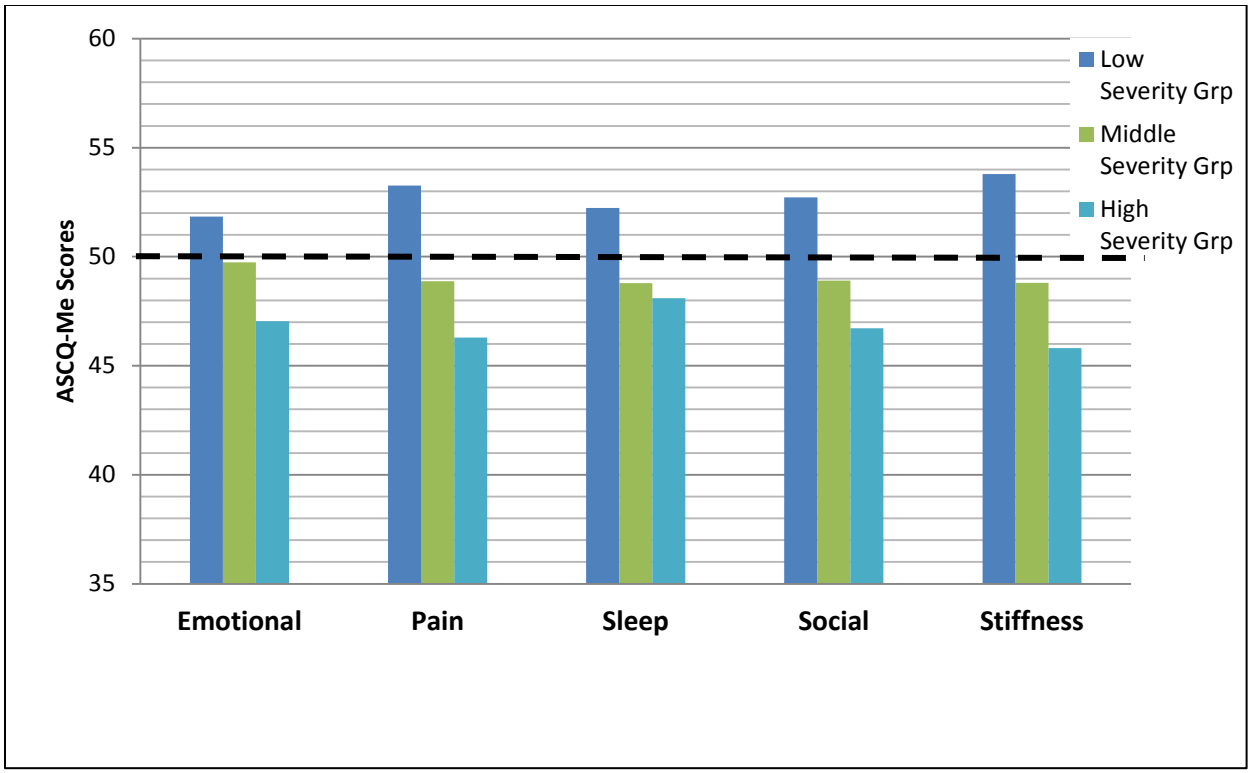
ASCQ-Me Adaptive and Short-Form Measures

Five of the ASCQ-Me measures (Emotional Impact, Social Functioning Impact, Pain Impact, Sleep Impact, and Stiffness Impact), both the adaptive and the short forms, are scored using the item response theory (IRT) model adopted in ASCQ-Me (i.e., the graded response model). The adaptive measures use computerized adaptive testing (CAT) technology in which a respondent's score is updated as each new question is answered, depending on his or her response to that particular question. For example, the computer will stop administering new questions once the estimated score is precise and accurate enough (i.e., the estimation error around the score is reduced to a certain level) or a certain number of questions are answered (e.g., 10). The final trait score (i.e., T-score) is the updated score after the last administered question is reported. The short form measures are scored using the same algorithm used for the adaptive measures. The only difference is that the score is not updated during the question administration process—instead, the trait score is estimated only after all the questions have been answered.

Score Interpretation

For ease of interpretation, each score is on the same scale, which was done by standardizing the scores to have a mean of 50 and a standard deviation of 10. The value of 50 indicates the health score of the average field test respondent, and the value of 10 represents one standard deviation unit. The ASCQ-Me field test sample was quite large (561 respondents). The diversity of the sample is described in Appendix A of this manual. However, because no recent, population-based, epidemiological studies have been conducted in the United States of adults who have SCD, how similar the field test sample is to the general population of those who have SCD is unknown. In the future, ASCQ-Me data should be collected on a representative sample of the SCD U.S. population in order to derive population based standard scores. Across all the question sets, a higher score always represents a healthier status. For instance, a score of 60 in the emotional impact measure indicates a respondent is healthier, in terms of his or her emotional state, than an average person in the SCD field test sample by one standard deviation. Exhibit 4-1 illustrates how ASCQ-Me short and long forms may be interpreted. The blue and turquoise bars show ASCQ-Me scores of patients at the least and highest severity tertiles, respectively, according to the SCD-MHC. The deep green bar represents the ASCQ-Me scores for the third of the sample with the lowest score on the SCD-MHC. There is a dose-response relationship between the ASCQ-Me scores and the SCD-MHC such that those with the highest ASCQ-Me scores (i.e. those who are most healthy according to ASCQ-Me) are also those with the lowest SCD severity according to the SCD-MHC.

Exhibit 4–1. Normative Interpretation of ASCQ-Me Short Form and Item Bank Scores



Mechanics of Scoring

If you administer the adaptive or short-forms of the Emotional, Social Functioning, Pain, Sleep, and Stiffness Impact question sets using the ASCQ-Me software, that software will automatically calculate the scores. You cannot administer the adaptive question sets by paper and pencil interview (PAPI). However, you can administer the short forms with PAPI. In that case, you must score the short forms yourself but the procedure is simple. The short forms are scored by summing the values for each response and using the conversion tables presented in Appendix B to obtain the score, which is on the same metric as the adaptive version. For example, if a person chooses the response to any short form item that denotes the worst health, the item for that person is valued at 1. Imagine that the person chooses the worst health response on all five items of the short form. That person's total raw score is 5. If this were the Emotional Impact short form, that person's score would be 26.8 on emotional impact.

With PAPI administration, a score can be approximated if a respondent skips one out of the five questions in a short form. However, a short form cannot be scored by hand if three or fewer items were answered. After confirming that four responses were provided on a short form, you should sum the response scores from the items that were answered, then multiply this sum by the total number of items in the short form (5), and finally, divide by the number of items that were answered (4). Alternatively, you could sum the response scores from the items that were answered, then multiply this sum by 1.25. For example, if a person chooses the response that denotes the worst health (response value=1) to four items in a short form and skips the fifth item, you would sum all responses (4), multiply by the number of items in the short form (5) and divide by the number of items that were answered (4). Here (4x5)/4=5. If the result is a fraction,

round up to the nearest whole number. This is a pro-rated raw score. You should then use the conversion table to translate the pro-rated score into a final score.

ASCQ-Me SCD Pain Episode Measure

The ASCQ-Me Pain Episode question set includes five questions regarding the frequency, timing, and severity of sickle cell pain events. Although "crisis" is a common term used to refer to these events, many prefer the term "pain episode." Nevertheless, our cognitive testing revealed that some respondents do not understand the use of the term "pain episode" to indicate the most severe, disabling sickle cell pain. In contrast, the phrase "pain attacks (crisis)" was interpreted as intended and so that is the phrase used in these questions.

The first question in the set asks about the number of pain attacks in the last 12 months (Item 1), while the second question (Item 2) asks about the timing of the most recent attack (e.g., < one week ago, 1–4 weeks ago, etc.). The remaining three questions ask about the severity of the *most recent* pain attack, including an overall rating of the severity of pain during the most recent attack on a scale from 0 to 10 (Item 3), the extent to which the pain attack interfered with the respondent's life (Item 4), and the duration of the attack (Item 5).

Score Interpretation

Two of the Pain Episode questions refer to frequency of pain episodes—one to a simple count of the number of attacks (more attacks indicate worse experience), and one to how long ago the most recent pain attack occurred. For these items, more pain attacks or having a more recent attack, respectively, is considered a worse experience. Three questions refer to the severity of pain during a pain episode: one question asks the respondent to rate the severity of the pain for the most recent attack, the second asks the respondent to indicate the degree to which the most recent attack interfered with his or her ability to be active, and the third refers to the duration of the pain attack. The rating item is on an 11-point continuous scale where a value of zero represents no pain and a value of 10 represents the "worst pain imaginable."

The response choices for the interference item correspond to concrete markers of increasingly severe experiences; that is, they correspond to more debilitating effects from a pain attack. A pain attack of a longer duration is considered more severe than one of a shorter duration. Note that all five items have an option with some variant of "I never had a pain attack." This response category is always initially coded as a 99. If you want to examine the frequency distribution of responses for each item in the Pain Episode question set, you should utilize the raw response scores. If Pain Episode composite scores are desired, you should first replace the raw response score of 99 with a zero, before calculating any composite scores.

The interpretation of the Pain Episode data at the *individual item response level* is straightforward as described above. The interpretation of these data at the *composite score level* requires more explanation. Most of the Pain Episode questions differ from one another in the number of possible response values; that is, some have values 0–7 and others 0–5 or 0–10. Moreover, the two composites, Pain Episode Frequency and Pain Episode Severity, have a different number of questions. This means that it is necessary to create standard scores in order for the two composite scores to be comparable to one another. How this is done is explained in the next section on "Mechanics of Scoring." Exhibit 4–2 shows some characteristics of the

distributions of the scores for each measure from the ASCQ-Me field test data that can help to interpret individual scores. These descriptive statistics have been rounded to the nearest whole number.

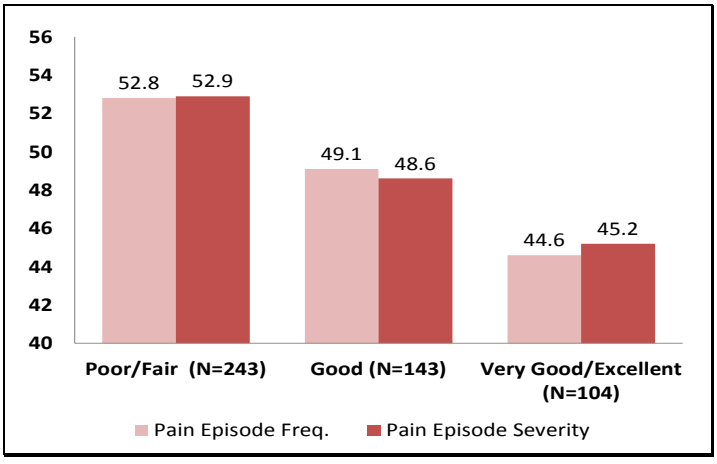
Exhibit 4–2. Pain Episode Scores: Indicators of Central Tendency and Variation[a]

	Mean[b]	Median[c]	Mode[d]	Standard Deviation[e]	Range[f]	Interquartile Range[g]
Pain Episode Frequency/Recency	50	52	56	10	21–64	12
Pain Episode Severity/Duration	50	52	52	10	15–66	14

[a]Note that higher scores indicate more severe pain episodes.
[b]Sum of the score distribution divided by the number of scores (490 scores).
[c]Score at the middle of the distribution of the scores ordered in ascending or descending order.
[d]Most frequent score.
[e]Square root of the sum of the deviations of individual scores from the mean.
[f]Lowest and highest score, respectively, that was observed in the ASCQ-Me field test data.
[g]The range of scores between the 25% and 75% of the score distribution.

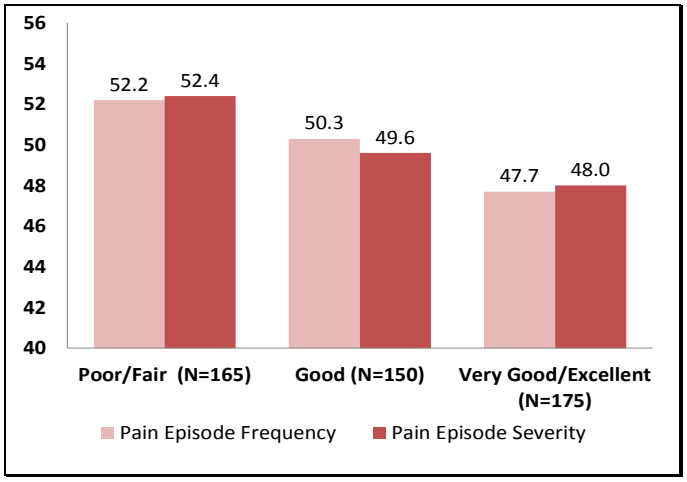
Just like the ASCQ-Me Emotional, Pain, Sleep, Social and Stiffness scores, the Pain Episode scores can be placed, immediately, relative to the average score for the ASCQ-Me field test respondents. This provides what is called "norm-based" interpretation, meaning that the score represents a comparison to a normal, or average score in some reference population. In this case the reference population is the 556 adults with SCD who answered ASCQ-Me questions during the field test. Appendix A describes the characteristics of this field test sample. However, unlike the other ASCQ-Me measures where a higher score is better; for the Pain Episode scores, a lower score is better. That is, a Pain Episode score of 60 would be one standard deviation *worse* than average and a score of 40 would be one-standard deviation *better*.

Exhibit 4–3. Pain Episode Scores at Different Levels of General Health Ratings



Thus, the interpretation of these Pain Episode scores is similar to that of the Adaptive Scores and Short Forms described in the previous section.

Exhibit 4–4. Pain Episode Scores at Different Levels of Overall Quality of Life Ratings



Interpretation of the Pain Episode scores also can be aided by viewing the scores for respondents who differ according to their overall ratings of their health and quality of life on the PROMIS global items. These data are shown in Exhibits 4–3 and 4–4, respectively. The graphs show the Pain Episode scores for people at the low, middle, and high range of each of these other indicators.

Mechanics of Scoring

Two separate composite scores can be produced by accumulating information from the five questions about Pain Episode: the Frequency composite represents the sum of the values for two of the items (see Exhibit 4–5) which results in a raw composite score with a potential range of 0 to 11. The Severity composite represents the sum of the values for the other three items (see Exhibit 4–6), which results in a raw composite score with a potential range of 0 to 22. Given the differences in number of responses for each question and number of questions in each composite, we recommend standardizing the composite scores so that they are on the same scale and can be compared. This was done by creating z-scores, which are also called standard scores, because this method makes scores derived from different raw score units comparable. The formula for a z-score is the individual score in question minus the mean of the score distribution divided by the standard deviation of the score distribution. Each person's score is expressed in standard deviation units. The means and standard deviations used to create z-scores for the Pain Episode Frequency and Severity measures are in the last rows of Exhibits 4–5 and 4–6, respectively.

Because the arithmetic used to create standard scores creates negative values as well as decimal values, it is customary to transform the scores. A popular transformation is to multiply the score by 10 so that the range of scores is greater than absolute 1 and add 50 so that the range of scores is positive. This is a "T-score transformation". [4]

[4] This T-score transformation is used for scoring the SF-36 Health Survey and PROMIS measures as well.

Exhibit 4–5. Scoring the Pain Episode Frequency Measure: Raw Scores Range from 0 to 11

PainEpisodeQ1. In the past 12 months, how many sickle cell pain attacks (crises) did you have?		PainEpisodeQ2. When was your last pain attack (crisis)?	
Response	**Score**	**Response**	**Score**
I did not have a pain attack (crisis) in the past 12 months	(99) 0[a]	I've never had a pain attack/crisis	(99) 0[a]
1	1	More than 5 years ago	1
2	2	1–5 years ago	2
3	3	7–11 months ago	3
4 or more	4	1–6 months ago	4
		1–3 weeks ago	5
		Less than a week ago	6
		I have one right now	7

Pain Episode Frequency Field Test Mean & Standard Deviation (n=490)	
Mean	**Standard Deviation**
7.525	2.573

[a]this response category is originally coded as a 99 but needs to be recoded as a zero before calculating composite scores.

Exhibit 4–6. Scoring the Pain Episode Severity Measure: Raw Acores Range from 0 to 22

PainEpisodeQ3. 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)?		PainEpisodeQ4. How much did your last pain attack (crisis) interfere with your life?		PainEpisodeQ5. About how long did your most recent pain attack (crisis) last?	
Response	**Score**	**Response**	**Score**	**Response**	**Score**
No pain	0	I've never had a pain attack (crisis)	(99) 0[a]	I've never had a pain attack (crisis)	(99) 0[a]
1	1	Not at all, I did everything I usually do	1	Less than 1 hour	1
2	2	I had to cut down on some things I usually do	2	1–12 hours	2
3	3	I could not do most things I usually do	3	13–23 hours	3
4	4	I could not take care of myself and needed some help from family or friends	4	1–3 days	4

PainEpisodeQ3. 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)?		PainEpisodeQ4. How much did your last pain attack (crisis) interfere with your life?		PainEpisodeQ5. About how long did your most recent pain attack (crisis) last?	
Response	**Score**	**Response**	**Score**	**Response**	**Score**
5	5	I could not take care of myself and needed constant care from family, friends, doctors, or nurses	5	4–6 days	5
6	6			1–2 weeks	6
7	7			More than 2 weeks	7
8	8				
9	9				
Worse pain imaginable	10				
I've never had a pain attack (crisis)	(99) 0[a]				

Pain Episode Severity Field Test Mean & Standard Deviation (n=490)	
Mean	**Standard Deviation**
15.018	4.275

[a]this response category is originally coded as a 99 but needs to be recoded as a zero before calculating composite scores.

ASCQ-Me SCD Medical History Checklist

The ASCQ-Me SCD Medical History Checklist (SCD-MHC) is a list of treatments and conditions associated with SCD with answers of "yes" or "no" to indicate whether or not the respondent has that condition or takes that treatment. The score for the checklist is simply the number of questions with a "yes" response. For example, some field test participants had as many as 8 indications of SCD severity: but no one endorsed all nine indications, so the field test scores ranged from 0 to 8.

Score Interpretation

The unit value for each question allows one to interpret the score as the number of conditions a person has which are associated with SCD. So, for this measure, a higher score means worse health. Correlations between the scores for this measure and those for the adaptive and short-form measures should be negative because the scores for those measures increase with increasing health. In contrast, correlations between the SCD-MHC and the pain episode scores should be positive because each measure increases with worse health.

The average SCD-MHC in the field test sample was 2.5.[5] Exhibit 4–7 shows the relationship of the SCD-MHC scores and overall health.[6] This provides a benchmark with which to interpret the SCD-MHC scores. For example, a SCD-MHC score of 1.0 is associated with reports of "excellent" health; whereas a SCD-MHC score of 2.2 is associated with reports of "fair" health.

Exhibit 4–7. SCD-MHC Scores at Different Levels of General Health

	In general, would you say your health is:				
	Excellent	Very Good	Good	Fair	Poor
Average SCD-MHC Score	1.0	1.3	1.9	2.2	2.6

This means that, in the field test, people who said their health was poor were likely to endorse around three indicators of SCD severity whereas those who said their health was excellent were likely to endorse one.

Mechanics of Scoring

To create a score for the SCD-MHC, simply sum the number of indicators endorsed.

More Information

Additional information about ASCQ-Me may be found at www.ascq-me.org, ascqmeinfo@air.org or 1-866-744-5746; or www.healthmeasures.net/ascq-me.

[5] When field test respondents were ordered according to their SCD-MHC score, people at the 25th percentile endorsed one indicator while those at the 50th and 75th endorsed two and three, respectively. Only 10 percent of respondents had four or more indicators of SCD severity out of nine. Most people endorsed two indicators.

[6] Data in Exhibit 4–7 are from the ASCQ-Me field test.

APPENDIX A: ASCQ-ME FIELD TEST RESPONDENTS

Interpreting the ASCQ-Me Field Test results requires an understanding of the source of the data, that is, the characteristics of the people who participated in the test. Exhibit A–1 summarizes the demographic characteristics of the survey respondents.

Exhibit A–1. Demographic Characteristics of Survey Respondents

Characteristic	Percent
Age	
18 to 24	29%
25 to 34	33%
35 to 44	20%
45 to 54	11%
55 to 64	6%
65 to 74	1%
Gender	
Male	36%
Female	64%
SCD Type	
Sickle Cell Anemia (SS)	64%
Sickle Hemoglobin C Disease (SC)	21%
Sickle Beta-Thalassemia Disease (Beta)	10%
Unspecified Sickle Cell Disease (Other)	5%

Adults with sickle cell disease (SCD) identified themselves as belonging to one of six age-range categories. While the majority was under 35 years old, those in the range of 65 to 74 years also participated. Nearly 1 in 5 participants was 45 years old or older. Sixty-four percent of respondents were women. Consistent with the population of patients affected, the majority of respondents were diagnosed with sickle cell anemia (hemoglobin SS), followed by hemoglobin SC and other variants.

To characterize the severity, frequency, and recency of severe vaso-occlusive incidents among field test participants. Respondents were asked how may sickle cell pain attacks or pain crises they had had in the past 12 months (Exhibit A–2).

Fifty percent indicated that they had not had a pain attack (crisis) in the past 12 months, while nearly 1 in 5 had had two or more in the past year. There was a range of experience with recency of pain attacks, with nearly 1 in 10 reporting that they were currently having a pain episode and the same percentage indicating that their last pain episode occurred more than a year ago. Approximately one-third had had a pain attack (crisis) within the past month.

Exhibit A–2. Frequency and Timing of Pain Episodes

Question	Percent
In the past 12 months, how many sickle cell pain attacks (crises) did you have?	
I did not have a pain attack (crisis) in the past 12 months	50%
0 times	18%
1 time	14%
2 times	9%
3 times	2%
4 or more times	7%
When was your last pain attack (crisis)?	
I never had a pain episode	1%
More than 5 years ago	1%
1–5 years ago	8%
7–12 months ago	7%
1–6 months ago	26%
1–4 weeks ago	28%
Less than a week ago	19%
I have one right now	9%

More than 60 percent of respondents indicated considerable suffering during their last pain attack, regardless of when that pain attack occurred. On a scale of 0-to-10 where 10 is the worst pain imaginable and 0 is no pain, almost 30 percent of respondents indicated that the pain was the "worst pain imaginable". An additional 34 percent rated their pain as severe, with ratings of 8 or 9 out of 10. In fact, the average rating of pain episode severity across all field test respondents was nearly 8, with 68 percent of individuals falling in the range of 6 to 9 (see last rows of Exhibit A–3).

The pain episode interference questions also demonstrated a great deal of variability in the field test respondents. When participants were asked to rate interference from pain during the last pain episode (Exhibit A–3), 37 percent indicated a great deal of interference—that is, they could not take care of themselves and needed some help from family or friends or constant care from family, friends, or health care providers. On the other hand, another 31 percent indicated that they experienced minimal to no interference. The majority of respondents indicated that their most recent pain episode lasted more than a day, with nearly 50 percent saying that it lasted more than the better part of a week. More than 20 percent suffered more than a week with their latest attack.

Exhibit A–3. Interference in Life Caused by Pain Episode(s)

Question	Percent
How much did your last pain attack (crisis) interfere with your life?	
I've never had a pain attack (crisis)	2%
Not at all; I did everything I usually do	10%
I had to cut down on some things I usually do	21%
I could not do most things I usually do	30%
I could not take care of myself and needed some help from family or friends	18%
I could not take care of myself and needed constant care from family, friends, doctors, or nurses	19%
About how long did your most recent pain attack (crisis) last?	
I've never had a pain attack (crisis)	2%
Less than 1 hour	4%
1–12 hours	18%
13–24 hours	8%
1–3 days	22%
4–7 days	25%
1–2 weeks	14%
More than 2 weeks	7%
Patient rating of severity of pain in last attack (0 to 10)	
Mean	7.76
Standard deviation	2.27

Taken together, the answers to these questions demonstrate a profound effect of pain episodes on a large proportion of the adult respondents with SCD, including their ability to function and the length of their suffering.

In addition to questions about pain episodes, respondents were asked about potential sequelae of SCD to characterize the severity of their condition. Respondents were asked to answer "yes" or "no" to questions regarding nine different conditions likely to be secondary to SCD and two treatments indicative of SCD severity. Exhibit A–4 displays the percentage of respondents that endorsed each of these.

The majority of respondents endorsed symptoms consistent with acute chest syndrome and reported taking pain medicine every day for SCD, as well as having had surgery to remove their gall bladders. Nearly 1 in 3 reported avascular necrosis and regular blood transfusions. Least frequently reported were retinopathy, stroke, leg ulcers, lung or kidney damage, or splenectomy.

Exhibit A–4. SCD Medical History Severity Markers

Item	Yes
Have you ever had severe chest pain along with trouble breathing?	69%
Are you taking pain medicine every day for your sickle cell disease?	52%
Have you had surgery to remove your gall bladder?	51%
Has DR/RN ever told you that you have damage to your hip or shoulder (avascular necrosis)?	34%
Are you getting regular blood transfusions for your sickle cell disease?	29%
Has DR/RN ever told you that you have eye damage (retinopathy)?	16%
Has DR/RN ever told you that you have had a stroke?	16%
Have you ever had open sores on your legs or feet (leg ulcers)?	14%
Has DR/RN ever told you that you have lung damage?	14%
Has DR/RN ever told you that you have kidney damage?	13%
Have you had surgery to remove your spleen?	9%

Respondents were also asked to indicate whether they had ever been diagnosed with any of a set of 12 chronic health conditions commonly found in the general population. These questions were adapted from the PROMIS measure of comorbid conditions and asked respondents whether a doctor or other health care professional (Dr/HP) had told them that they had the condition. The percentage responding "yes" to each of these is presented in Exhibit A–5.

Exhibit A–5. Frequency of Chronic Health Conditions Among Respondents

Item	Yes
Ever told by a Dr/HP that you have migraines or severe headaches?	29%
Ever told by Dr/HP that you have asthma?	24%
Ever told by Dr/HP that you have a mental illness that requires medicine?	10%
Ever told by Dr/HP that you have rheumatoid arthritis?	9%
Ever told by Dr/HP that you have diabetes or high blood sugar or sugar in your urine?	7%
Ever told by Dr/HP that you have chronic lung disease (COPD) or chronic bronchitis or emphysema due to smoking?	6%
Ever told by Dr/HP that you have Hepatitis C?	5%
Ever told by Dr/HP that you had a heart attack (myocardial infarction)?	4%
Ever told by Dr/HP that you have hardening of the arteries (coronary artery disease)?	3%
Ever told by Dr/HP that you have an alcohol or drug problem?	3%
Ever told by Dr/HP that you have cancer (other than non-melanoma skin cancer)?	2%
Ever told by Dr/HP that you have HIV or AIDS?	1%

Migraine or severe headaches were reported most often (29 percent) followed by asthma (24 percent). Mental illness, rheumatoid arthritis, diabetes, chronic lung disease, and hepatitis C were reported by 5–10 percent of respondents. Fewer than 5 percent of respondents reported the comorbidities of heart attack, coronary artery disease, alcohol or drug problems, cancer, and HIV/AIDS

APPENDIX B: SCORING TABLES FOR THE FIVE STATIC SHORT FORMS

Emotional Impact Short Form Conversion Table		
Raw Score	T-Score	SE[a]
5	26.8	4.5
6	30.8	3.5
7	33.3	3.1
8	35.3	2.9
9	37.0	2.8
10	38.5	2.7
11	39.9	2.6
12	41.2	2.6
13	42.5	2.6
14	43.7	2.6
15	44.9	2.6
16	46.2	2.7
17	47.4	2.7
18	48.7	2.8
19	50.1	2.8
20	51.5	3.0
21	53.3	3.3
22	55.2	3.6
23	57.3	3.8
24	60.5	4.4
25	65.6	5.8

[a]SE = Standard Error for T-Score

Social Functioning Impact Short Form Conversion Table		
Raw Score	T-Score	SE[a]
5	26.0	4.3
6	29.8	3.2
7	32.5	2.8
8	34.7	2.8
9	36.8	2.7
10	38.7	2.7
11	40.4	2.7
12	42.1	2.7
13	43.9	2.6
14	45.6	2.6
15	47.2	2.6
16	48.8	2.6
17	50.5	2.6
18	52.2	2.5
19	54.0	2.5
20	55.8	2.5
21	57.7	2.5
22	59.8	2.6
23	62.1	2.7
24	64.9	3.1
25	69.8	4.6

[a]SE = Standard Error for T-Score

Pain Short Form Conversion Table		
Raw Score	T-Score	SE[a]
5	24.8	3.9
6	28.8	2.5
7	31.0	2.2
8	33.0	2.2
9	34.9	2.2
10	36.7	2.2
11	38.3	2.2
12	39.9	2.1
13	41.5	2.1
14	43.0	2.1
15	44.4	2.1
16	45.7	2.1
17	47.1	2.1
18	48.5	2.0
19	49.9	2.0
20	51.2	2.0
21	52.5	2.0
22	54.0	2.1
23	55.8	2.3
24	58.0	2.8
25	63.8	5.2

[a]SE = Standard Error for T-Score

Stiffness Short Form Conversion Table		
Raw Score	T-Score	SE[a]
5	24.9	4.0
6	29.0	2.8
7	31.5	2.5
8	33.5	2.4
9	35.3	2.4
10	36.9	2.3
11	38.4	2.3
12	39.9	2.3
13	41.3	2.3
14	42.7	2.3
15	44.0	2.3
16	45.4	2.3
17	46.7	2.3
18	48.1	2.3
19	49.5	2.3
20	51.0	2.5
21	52.7	2.7
22	54.7	2.9
23	57.0	3.3
24	59.9	3.8
25	65.4	5.4

[a]SE = Standard Error for T-Score

Sleep Short Form Conversion Table		
Raw Score	T-Score	SE[a]
5	27.9	4.4
6	32.3	3.1
7	35.1	2.7
8	37.3	2.6
9	39.5	2.6
10	41.4	2.6
11	43.2	2.6
12	45.0	2.6
13	46.7	2.5
14	48.2	2.5
15	49.7	2.4
16	51.1	2.4
17	52.5	2.4
18	53.9	2.4
19	55.3	2.4
20	56.7	2.4
21	58.2	2.5
22	59.9	2.7
23	61.9	3.0
24	64.4	3.4
25	69.1	4.8

[a]SE = Standard Error for T-Score