

# **QUESTIONNAIRE ADMINISTRATION MANUAL**

**THE SOUTH CAROLINA TRAUMATIC BRAIN  
INJURY FOLLOW-UP REGISTRY  
(SCTBIFR)**

Version 1.0  
09/8/03

**MEDICAL UNIVERSITY OF SOUTH CAROLINA  
SOUTH CAROLINA DEPARTMENT OF DISABILITIES AND SPECIAL NEEDS  
SOUTH CAROLINA DEPARTMENT OF HEALTH AND  
ENVIRONMENTAL CONTROL**

**PRINCIPAL INVESTIGATOR**  
Anbesaw Selassie, DrPH

**CO-INVESTIGATOR FOR RESEARCH AND FOLLOW-UP**  
Elisabeth Pickelsimer, DA

**PROJECT COORDINATOR & DATA MANAGER**  
Wes Gravelle, MPH

**INTERVIEWERS**  
Sally Broadhurst, OTR, Lead Interviewer  
Robin Butler, BS, Interviewer  
Jennifer Clifford, MA, Emeritus Interviewer  
Timothy Hickman, BA, Interviewer  
Sharon Stokes, BS, Interviewer  
Kimberly Workman, BS, Interviewer

**STATISTICIANS**  
Ja Kook Gu, MPH  
Pamela L. Ferguson, PhD

**CDC TECHNICAL OFFICER**  
Jean A. Langlois, ScD, MPH

Project Office  
(803) 935-5307

The South Carolina Traumatic Brain Injury Follow-up Registry Participant Interview and accompanying documents were developed under a Cooperative Agreement from the Division of Disability and Injury Prevention and Outcome Programs of the National Center for Injury Prevention and Control, Centers for Disease Control and Prevention (Award Number U17/CCU421926).

## Table of Contents

GENERAL ADMINISTRATION.....	4
TELEPHONE SCRIPTS.....	14
QUESTION-BY-QUESTION GUIDE.....	19
PROXY SCREEN/DEMOGRAPHICS.....	20
PARTICIPANT INFORMATION.....	21
MULTIPLE CONCUSSIONS.....	23
ALCOHOL AND DRUG ASSESSMENT.....	30
POST-INJURY SYMPTOMS.....	33
VIOLENCE SCREEN - PERPETRATOR.....	35
SELF-RATED DISABILITY.....	37
EMPLOYMENT.....	38
SERVICE NEEDS - EMPLOYMENT: NOT WORKING.....	40
EMPLOYMENT- WORKING.....	42
SERVICE NEEDS - EMPLOYMENT: WORKING.....	43
ACTIVITIES OF DAILY LIVING.....	45
VIOLENCE SCREENER - NEGLECT.....	47
INSTRUMENTAL ACTIVITIES OF DAILY LIVING.....	48
SERVICE NEEDS - PERSONAL ASSISTANT/PERSONAL CARE ATTENDANT.....	50
MARITAL STATUS AND LIVING SITUATION.....	52
SERVICE NEEDS - INCREASING INDEPENDENCE.....	53
SOCIAL INTEGRATION.....	54
SOCIAL SUPPORT.....	55
SERVICE NEEDS - INFORMATION, CASE COORDINATION, MENTAL HEALTH.....	56
VIOLENCE SCREEN - PHYSICAL AND SEXUAL ABUSE.....	58
TRANSPORTATION.....	59
SERVICE NEEDS - TRAVELING.....	60
INSURANCE.....	61
EDUCATION.....	63
INCOME.....	65
SERVICE NEEDS - 1 MOST IMPORTANT.....	67
PARTICIPANT CONTACT INFORMATION.....	69
INTERVIEW INFORMATION.....	70
CRISIS PROTOCOL.....	73

## GOAL AND DESIGN OF THE QUESTIONNAIRE ADMINISTRATION MANUAL

### Goal of the Manual

The goal of the questionnaire manual is to ensure the standardized administration of the South Carolina Traumatic Brain Injury Follow-up Registry (SCTBIFR) Participant Year One Questionnaire. In order to have reliable and valid results, all questions must be asked **exactly as they are written**, using standard definitions and consistent probes. The interviewer should become familiar with the content of the manual before administering the questionnaire. In addition, the interviewer should be thoroughly familiar with the purpose of each section and refer to the manual at any time during the interview to clarify and answer questions.

### When to Use This Manual

If the respondent has difficulty answering the question, **first repeat the question exactly as worded**. If the respondent still has difficulty, **next use a neutral probe** to encourage a response. (See appropriate section of the Interviewer Manual for examples.) If further clarification is needed or if the respondent asks specifically for the meaning of a word or phrase, consult this manual to determine if a definition or clarifying phrase has been provided for your use in facilitating the respondent's understanding of the question. These phrases should be worded in a neutral manner so as not to unduly influence the response. Note that not all questions will have a definition or clarifying phrase provided. For these questions, **ask the question as written**. However, make a note of the problem encountered and report it on a Decision Log form, if appropriate. (See attached form.) The questionnaire manual is updated and revised as new clarifications and definitions are added.

### Manual Design

This questionnaire manual is divided into sections. The "General Administration" section describes the general layout and questionnaire formatting, e.g., the use of bolding, brackets and skip patterns.

The "Introduction Materials" section provides scripts and information to introduce the study to participants. This is the guide for what will be said to answer questions about the study, and to provide interviewers with scripts to use when leaving messages on answering machines.

The "Question-by-Question Guide" provides the purpose of each section, probing questions where needed, and definitions or clarifications pertaining to specific questions. This section can be easily referred to at any time during the questionnaire administration. The interviewer can glance from the computer screen containing the interview questions to the appropriate manual page to find definitions, clarifications, or probes. Interviewers should be thoroughly familiar with the purpose of each section and readily use the provided probes and definitions.

The “Decision Log” is to be used to document problems encountered in interviewing, resolve these problems in a standardized way, and correct and re-enter data when necessary so that responses are coded consistently. An interviewing problem includes: (a) any item for which the interviewer perceives a need to deviate (even a little) from the actual wording of the question as it is written on the questionnaire to facilitate a response, (b) any question for which an accurate code for the response given by the respondent is not available among the choices on the questionnaire, and (c) any other issue that arises during the interview. The Decision Log form, along with instructions for its use, is located in the “Decision Log” section of the manual.

The “Crisis Protocol” addresses two categories of crisis: (1) medical, safety and psychological emergencies, (2) psychological distress (non-emergent). If during an interview, the interviewer suspects that the respondent is at risk for medical, physical or psychological harm, the crisis protocol should be followed and the action taken documented on the appropriate form. The crisis protocol and forms are located in the “Crisis Protocol” section of the manual.

## GENERAL ADMINISTRATION

### Interviewer Materials

The interviewer should have the following items available before beginning an interview.

1. Computerized questionnaire or paper questionnaire, if computer unavailable or other appropriate questionnaire version
2. Paper and pencil to record any questions or responses
3. *Questionnaire Administration Manual*
4. Telephone, preferably with headset
5. Clock or watch (if using paper form)

### Which Questionnaire to Use: Standard, Proxy, Mail-out, Prisoner, Year 2

Purpose: Different questionnaires provide alternative methods of gathering information from and/or about the participant.

Instructions:

#### Standard (First Interview)

The standard questionnaire is used for telephone administration to either the participant or the proxy. When calling to interview, always ask to speak with the participant. If the participant is available to be interviewed, administer the questions in the “Participant Information” section to determine if the participant is able to adequately complete the interview. If so, proceed with the interview.

#### Proxy

The proxy questionnaire is incorporated into the standard questionnaire. If the person who answers the telephone says that the participant cannot respond (e.g., is in a coma or has limitations which prevent completing an interview), note the specific limitation on the “Participant Information” sheet. Ask if the person speaking is a family member or someone who knows the participant well and is willing to serve as proxy (or if another person is more appropriate). If the potential proxy agrees to answer for the participant, use the specified proxy questions of the interview. Proxy questions are sometimes different due to wording changes and specific questions which are not asked. The wording of some questions changes from you or your to he/she or his/her. The following sets of questions are not to be asked of a proxy—

- LIS (life satisfaction)
- SRD (self-rated disability)
- VIO (violence).
- Spirituality

Computerized data base

The majority of first interview data collection will be via the computerized version, thus allowing for direct data entry which lessens the probability of keystroke errors. This method alerts the interviewer if data entered are out of range or in an incorrect format.

Note: In the computerized version, instructions which apply to all questions in the section will be found in the variable field for the first question of the section.

Mail-out

The mail-out questionnaire (paper booklet) is reserved for special circumstances in which either the participant or proxy is willing or able to respond only in written form.

Prisoner

Use the prisoner questionnaire with individuals who are incarcerated at the time of the interview. When administering this version, please note that some wording changes and some questions are not asked for this special population.

Example:

## [PRISONER QUESTIONNAIRE]

GEH-21: If you were not in prison, during the past 4 weeks, how much would **pain** have interfered with your normal work, including both work outside the home and housework? Would it have interfered...

- 1=Not at all
- 2=A little bit
- 3=Moderately
- 4=Quite a bit
- 5=Extremely
- 777=*Refused*
- 888=*Don't Know*
- 999=*Not Applicable*
- 888=*Don't know*
- 999=*Not Applicable*

## [STANDARD QUESTIONNAIRE]

GEH-21: During the past 4 weeks, how much did **pain** interfere with your normal work, including both work outside the home and housework? Did it interfere...

- 1=Not at all
- 2=A little bit
- 3=Moderately

4=Quite a bit  
 5=Extremely  
 777=*Refused*  
 888=*Don't Know*  
 999=*Not Applicable*

### Year 2

Use the Year 2 questionnaire to interview those persons who participated in the first interview. The phrase “Since your injury on [DATE]” has been replaced in this questionnaire with “Since the last time we talked with you on [DATE]...” and is used so often that it becomes too repetitious. Interviewers may use their discretion as to when it would be appropriate to change the introductory clause to alternate wording for the time frame such as “Since the last time we talked with you about a year ago” or “Since the last time we talked with you about nine months ago.” Calculating the time span since the previous interview can help decide this wording.

Example:

SDN-08: **Since the last time we talked to you on (DATE)**, have you **received** help increasing your independence in housekeeping, cooking, or shopping?

1=Yes [GO TO SOCIAL INTEGRATION]

2=No

777=*Refused*

888=*Don't Know*

999=*Not Applicable*

Alternate introductory phrase:

SDN-08: **Since the last time we talked with you about a year ago**, have you **received** help increasing your independence in housekeeping, cooking, or shopping?

1=Yes [GO TO SOCIAL INTEGRATION]

2=No

777=*Refused*

888=*Don't Know*

999=*Not Applicable*

### Sections and Order

Purpose: The questionnaire is divided into 28 sections arranged according to topic, importance, and sensitivity.

Instructions: Follow the order of the sections and questions as they appear in the questionnaire.

### Question Type

Purpose: Closed-ended questions require an answer from among a specific set of choices. Responses are either yes/no or from a specified list. Follow the individual question instructions regarding whether the list should be read to

the respondent.

Example: EPN-05: Would you **like to work** in a job for which you get paid?  
 1=Yes  
 2=No  
 777=*Refused*  
 888=*Don't Know*  
 999=*Not Applicable*

Note: A few questions are left open-ended and therefore have no standard response. Responses to these questions are to be recorded exactly (verbatim) as reported.

Example:

SDN-14: Is there an important need that you have now that I have not asked about?  
 1=Yes SDN-14s:Specify\_\_\_\_\_

2=No  
 777=Refused  
 888=Don't Know  
 999=Not applicable

### Clarifications

Purpose: Provides the interviewer with a phrase that can be read aloud to explain the meaning of the question if the respondent requests a clarification. Clarifications can be found in this manual and follow the order of the questionnaire. Clarifications also can be found in the drop down boxes for the computerized version of the interview.

Example: ADL-03: By yourself and without using any special equipment, how much difficulty do you have **eating**? Is it...

Clarification: Eating means feeding yourself, cutting food, holding a fork, or drinking from a glass.

1=None  
 2=Some  
 3=A lot  
 4=Unable to do  
 777=*Refused*  
 888=*Don't Know*  
 999=*Not Applicable*

### Bolding

Purpose: The use of **bolding** signals the main point of the question and/or a change in time frame.

Instructions: Bolded words should be stressed and emphasized in order to alert and inform the respondent.

Example: SDN-07: SDN-07: **Since your discharge from the hospital on (DATE)**, have you **received** help from a paid personal assistant or personal care attendant?  
 1=Yes  
 2=No  
 777=*Refused*  
 888=*Don't Know*  
 999=*Not Applicable*

### Brackets

Purpose: Words typed in uppercase and contained within brackets are notes to the interviewer.

Instructions: These comments should **not** be read out loud to the respondent. Instead they are used to direct and cue the interviewer.

Example: PAI-10: Do you have any problems hearing me?  
 1=Yes [Should a PROXY be interviewed?]  
 2=No  
 777=*Refused*  
 888=*Don't Know*  
 999=*Not Applicable*

### Skip Patterns

Purpose: Provide instructions as to the next appropriate question based on the respondent's response. Skip patterns are found to the right of the response option and they always appear in brackets and uppercase letters. They begin with the instructions [GO TO..].

Example: SDN-04: Since your discharge from the hospital on (DATE), have you **received** help finding places and opportunities to socialize with others?  
 1=Yes [GO TO ACTIVITIES OF DAILY LIVING]  
 2=No  
 777=*Refused*  
 888=*Don't Know*  
 999=*Not Applicable*

### Reading of Response Categories

Purpose: To make respondent aware of the response choices.

Instructions: For those sections in which sequential, multiple questions have the same response choices, the general rule is to read all of the response categories verbatim for the first **three** questions. If on the fourth question, the respondent is familiar with the response options, it is no longer necessary to read them. Although the interviewer should be prepared to repeat the responses again later in the sequence of questions, this only needs to be done if the respondent appears to be having difficulty recalling them.

Time Frame

Purpose: To remind the respondent of the reference time period when answering the question.

Instructions: Repeat phrases such as “since your injury” or “before your injury” for the first **three** questions in a sequential section. On the fourth question, this phrase may be omitted and only the main part of the question read. Continue to read the complete question if it is sensed that the respondent needs to be reminded of the appropriate time frame.

The time frame “before your injury” generally refers to the 12-month preceding the injury date.

Probing

Purpose: To stimulate a response or clarify the meaning of the question.

Instructions: If the respondent has difficulty answering the question, **first repeat the question exactly as worded**. If the respondent still has difficulty, **next use a neutral probe** to encourage a response. (See appropriate section of the interviewer manual for examples.) If further clarification is needed or if the respondent asks specifically for the meaning of a word or phrase, consult this manual to determine if a definition or clarifying phrase has been provided for use in facilitating the respondent’s understanding of the question. These phrases should be worded in a neutral manner so as not to unduly influence the response. If the respondent still questions the meaning, code the response as “Don’t Know.” Note that not all questions will have a definition or clarifying phrase provided. For these questions, **ask the question as written**. However, make a note of the problem encountered and record it on a decision log form if appropriate.

Transitional Phrases

Purpose: To aid the interviewer in introducing a new section or sensitive question.

Instructions: Read aloud, as written.

Example: “Some people have trouble finding out how to get help that they need after a head injury. I am interested in knowing whether you feel you need the following kinds of help but for one reason or another you have not received them.”

Coding

Purpose: The following codes are used universally throughout the questionnaire.

Yes	is coded as “1”
No	is coded as “2”

Refused is coded as "777"  
 Don't know is coded as "888"  
 Not applicable is coded as "999"

Note1: "Not applicable" is a legitimate response only if a skip pattern allows the question to be omitted.

Note2: In very special situations, such as when a participant is in persistent coma, NA is used for sub questions like ADLs. The code (555) denotes a combination of does not apply. An explanation of the reason should be recorded in the interviewer comments at the end of the survey.

Note3: Coding conventions may vary according to the question.

Example: GEH-01: In general would you say your health is...  
 1=Excellent  
 2=Very Good  
 3=Good  
 4=Fair  
 5=Poor  
 777=*Refused*  
 888=*Don't Know*  
 999=*Not Applicable*

Instructions: If you are uncertain about how to code a response, write down the question number and verbatim response and complete a Decision Log form after the interview is finished.

**"Specify"** Responses of "specify" require the interviewer to write in the response exactly as stated by the respondent. This response is used when the respondent's response does not fit any available category or to better define a response.

Example: EDU-02a: **Since your injury**, have you graduated or earned a degree?  
 1=Completed grade 8  
 2=Completed grade 12  
 3=Completed a two-year college or technical school program  
 4=Graduated from a four-year college or university  
 5=Other EDU-02a-s: Specify

---

777=*Refused*  
 888=*Don't Know*  
 999=*Not Applicable*

Instructions: If the interviewer feels uncertain as to whether a "Specify" response belongs to an existing category, they can ask for the code to be determined by the Scientific Advisors. An interviewer may elect to fill out a Decision Log for "Specify" on a question like the following example.

Example: LIV-03: Where do you live **now**?  
 1=Private residence such as a house, apartment, mobile home (trailer)  
 2=Group home or transitional living center  
 3=Assistive living facility where someone helps you

- 4=Correctional institution
- 5=Nursing home or other long-term care facility
- 6=Foster home
- 7=Inpatient psychiatric hospital
- 8=Homeless shelter
- 9=Military barracks or college dormitory
- 10=Boarding school
- 11=Other           LIV-03s:Specify: bus station in Greenville
- 777 =*Refused*
- 888= *Don't Know*
- 999=*Not Applicable*

**“Record Quote”**      Responses of “record quote” also require the interviewer to write in the responses exactly as stated by the respondents. In some cases these quotes will need to be matched with specified responses after the interview.

Example:      What is the **main** reason you have **not** received help controlling alcohol or drug use?  
 1=You did not know where to get help  
 2=You did not have the money or insurance to pay for help  
 3=You did not have a way to get there  
 4=It was too far away  
 5=It was not offered during a time when you could go  
 6=You did not qualify for help  
 7=You could not get a referral  
 8=You have contacted someone and are waiting to receive help  
 9=Any other reason?  
 777=Refused  
 888=Don't Know  
 999=Not Applicable  
 SDN-01t: Record quote and match:” \_\_\_\_\_”

Service Needs (SDN): Reason not received

**Purpose:**      To determine whether participants have received each service after injury; whether they feel they need each service; and if they need it, why haven't they received it.

**Instructions:** Read question and pause for answer. If the respondent spontaneously responds, record their answer verbatim. Match this answer to one of the existing response options. If the response can not be coded promptly using existing categories, record as “9=any other reason.” If the respondent does not answer, read the choices slowly and allow only one main reason.

**Note:**      After the response, clarify with, “So the **main** reason you have not received help is [repeat the response].”

Example:      What is the **main** reason you have **not** received help controlling alcohol or

drug use?

1=You did not know where to get help

2=You did not have the money or insurance to pay for help

3=You did not have a way to get there

4=It was too far away

5=It was not offered during a time when you could go

6=You did not qualify for help

7=You could not get a referral

8=You have contacted someone and are waiting to receive help

9=Any other reason?

*777=Refused*

*888=Don't Know*

*999=Not Applicable*

SDN-01t: Record quote and match:” \_\_\_\_\_”

## INTRODUCING THE STUDY

For participant/proxy whose signed consent form **was received** prior to the interview:

“Hello, my name is \_\_\_\_\_ and I’m calling from the Medical University of South Carolina. May I speak with Ms., Mr., Mrs. \_\_\_\_\_? How are you today? We are doing a study where we talk to people in South Carolina who have been hospitalized with a head injury. Thank you for returning the form I sent you. Do you have any questions? Your experiences are very important and will help us understand what life is like after a head injury. The interview should take about 45 minutes to complete. After you finish the interview, you will receive a \$15 check in the mail in appreciation for your time. If it is all right, I’d like to begin now with some questions about you.”

SC Traumatic Brain Injury Follow-up Registry

**TELEPHONE SCRIPTS**

What should you say to a.....

**Contact**

- F “ Hello my name is \_\_\_\_\_. I’m calling from the Medical University of South Carolina. I am trying to get in contact with [participant’s name] and they have you listed as someone who would know where to reach them. We tried reaching them at [participant’s address and phone number]. Do you have a more current phone number or address?
  
- F “Could I leave our toll-free number for [participant’s name] and would you have a way to get this message to them and have them call me here? Thank you for your assistance”

**Employer**

- F “Hello my name is \_\_\_\_\_. I’m calling from the Medical University of South Carolina. I would like to speak with or leave a message for your employee [participant’s name].”
  
- F [If the participant no longer works there ask:] “ Would you have a current phone number, address, or way to get in touch with them?”

## SC Traumatic Brain Injury Follow-up System

### LEAVING MESSAGES

How to leave a message for a ...

#### Participant

- F “Hello, my name is \_\_\_\_\_. I’m calling from the Medical University of South Carolina. I would like to speak to [participant’s name] about the letter we recently mailed to him/ her. Please return this call on our toll-free number at 1-877-357-8839. Leave a message with a phone number and a good time to call you. Thank you in advance for your assistance.”

#### Contact

- F “Hello, my name is \_\_\_\_\_. I’m calling from the Medical University of South Carolina. I am trying to get in contact with [participant’s name] and they have you listed as someone who would know where to reach them. I would like to speak with you. Please call our toll-free number 1-877-357-8839 and leave a message with your phone number and a good time to call you. Thank you in advance for your assistance.”

## ANSWERS TO COMMON QUESTIONS

Answers to these questions are taken from information included in the South Carolina informed consent form as well as from the Colorado document “Most Frequently Asked Questions.” The interviewer can translate these answers into their own words while retaining the accuracy of the information. The statements in parentheses are additional information that may or may not be helpful depending on the particular situation.

If the interviewer is unable to answer a specific question, she or he can do the following:

- a. Tell the participant you will get the answer and call them back.
- b. Ask the project manager to call the participant back.
- c. Give the participant the project manager’s name and phone number.

1. How did you get my name?

When a South Carolina hospital treats someone who has had a head injury, it must report this to the South Carolina Department of Disabilities and Special Needs. (This department helps people in South Carolina get services they need.) During the last year, you had a head injury and were treated in a hospital. This is how the Department of Disabilities and Special Needs got your name.

2. What is the purpose of this follow-up study? Why do you want to talk with me?

The purpose of this follow-up study is to find out if and how the lives of people with head injuries have changed since their injury. This will help us learn about how well people who have had head injuries return to active lives and what problems they face. What we learn in this project will help South Carolina policy makers and service providers understand better the needs of people.

3. How long will this take?

It really depends on how you answer the questions, but most people take about 45 minutes. (If some questions do not apply to your particular situation and you move quickly through the interview it could take less).

4. How many people answer these questions?

Each year we will ask about 1,000 people to take part (who have been hospitalized with a head injury during the previous year.) We also ask those who participated in the initial interview to answer questions for us in additional years so that we can document any changes over time.

5. Will my name be used?

No. All that we talk about will be kept private to the extent allowed by law. Your name or other facts that might point to you would not appear when we present this study or publish its results. (We are interested in the combined responses of all the people that answer these questions.)

6. What kind of questions will you ask?

I will ask you questions about your health, both before and after your injury. I will also ask about your work or school, and services you have used or need to help with your injury. Some of the questions ask about alcohol use, illegal drug use, and depression.

7. What are the risks to me? Can I lose my benefits? Are you going to give this information to my doctor or caseworker?

We know of no risk to you by taking part in this interview. We will not talk to anyone about you. You will not lose any benefits or services to which you are entitled by refusing to take part or by withdrawing from the project. (Your answers are private and confidential. This information will not be released to anyone except you.)

8. What do you want from me?

I am asking you to answer questions about your health and your injury over the telephone.

9. Who is sponsoring/doing this project?

The Medical University of South Carolina is doing the follow-up with help from the Centers for Disease Control and Prevention. (The South Carolina Department of Disabilities and Special Needs and the Department of Health and Environmental Control also contribute to the project).

10. How will the results be used?

The results will be used to help South Carolina policy makers and service providers better understand the needs of people with head injuries.

11. How do I know this will be kept confidential?

All of us working on this project are required to follow policies and procedures designed to protect your confidentiality. No information that would permit anyone to identify you will be released or published.

12. What will I get out of it?

You will be helping South Carolina to better understand the needs of people with head injuries. After the interview, you will be eligible to receive \$20. This will help repay you for your time spent during the interview.

13. I'm okay, why do you want to talk with me?

To get an accurate picture of what happens after a head injury, we need to talk with as many people as possible, including people like you who have not had any long-term effects or complications. Your feedback is very valuable to this project.

14. When did this project start? How long has the state been doing this?

The Centers for Disease Control and Prevention started working with us in 1998. (The first people to be interviewed were persons injured in 1999.)

15. How many other states do this?

Although other states may have some form of follow-up with persons with head injury, South Carolina is only the second state in the country to work with the Centers for Disease Control and Prevention to develop a formal statewide follow-up of people with brain injuries. (The first state is Colorado.)

16. Why are you calling me? I don't have a head injury?

We are calling everyone who was hospitalized.

## QUESTION-BY-QUESTION GUIDE

Upon contacting the potential participant, the individual may deny that he or she had a head injury. This will be especially true of those persons who were hospitalized with another condition as the primary diagnosis. In this case the following probe can be used.

Probe: Your name was given to us because you were in the hospital. It would be helpful to us if you would answer our questions even though you may not have problems.”

If the potential participant still does not want to participate, be courteous and end the conversation. The person cannot be interviewed without consent.

Every now and then a potential participant will mail back the introductory letter along with the dollar bill and state that he or she did not have a head injury. If this individual also indicates on the consent form “Do not contact,” we will not contact. However, if the situation occurs without the consent form being returned, call the participant and continue with the above probe.

### INTERVIEW INFORMATION

INI-01 Interview Date Date will be automatically calculated by computer.

INI-02 Beginning Time Time will be automatically calculated by computer.

INI-03 Interviewer’s Initials Record as first, middle, and last initials of interviewer

INI-04 Number of Contacts

Definition(s):

Contacts - Number of telephone calls, including interview call, made to locate participant. Number should match the calls recorded on the “Participant Tracking Sheet.”

INI-05 Version Number Revision number indicated on questionnaire/computer

INI-08 Informed Consent Type of consent received [either mailed or verbal]

PROXY SCREEN/DEMOGRAPHICS

**Purpose:** Questions asked to a family/friend or caregiver when it is determined that the participant is incapable of self reporting OR if a parent or guardian elects to report for their 15 to 17 year-old child.

**Note:** The questions are to be read to the proxy as stated. If proxy asks whether to respond as the proxy would or as the participant would— Probe: “What would **you** say?”

**PRX-03** Proxy age. To participate, the proxy is required to be a minimum of 18 years of age.

**PRX-05** Response to this question is to be coded as to the respondent’s relationship with the participant.

**PRX-08** Can participant respond to telephone survey?  
If the respondent states that participant has the ability to respond, ask to speak with participant.

**PRX-10** If respondent reports that the participant cannot respond due to an inability to know what’s going on, follow the response with “Can [participant’s name] consistently follow a command like “Open and close your eyes?”” If the response is “no” and no other justification is given for the inability, code as 1=cannot follow commands.

**PRX-11 and PRX-12** The purpose of these two questions is to serve as a screener as to whether the individual should be accepted as a proxy. If the respondent does not answer “yes” to both questions, do not continue to interview this person. Ask if another person is available who knows the participant and would be willing to participate in the interview.

Clarification: “Specific questions” refers to knowledge of the participant’s health and activities such as work.

**PRX-13** Note: The interviewer has the final authority to accept or reject the respondent as a proxy based upon the response to this question.

**PRX-18** Proxy acceptable  
If proxy is deemed unacceptable, do not continue to interview.

PARTICIPANT INFORMATION (page #s or screen #s)

Purpose: To establish rapport and determine if the participant is able to participate or if a proxy respondent is needed

Instructions: Complete this section and, if you are unsure about the ability of the participant to complete the interview independently, continue with the next section to determine whether a proxy is needed.

## PAI-06 Participant Date of Birth

PAI-06a-c Age consistent with "Participant Information Sheet"  
 DOB consistent with "Participant Information Sheet"  
 DOB and age mathematically consistent.

Instructions: The interviewer is to answer these questions by comparing the respondent's response with the "Participant Information Sheet." Do not read questions a-c aloud.

Note: If there is a wide discrepancy between the response and the Participant Information Sheet, we will need to determine which is correct and revise the incorrect date.

## PAI-07a Date of Injury Correct

Instructions: The date of injury may be inconsistent for patients who were transferred to the discharging hospital. Correct on a case-by-case basis. Keep in mind that some participants may be unable of remembering these dates.

## PAI-08 Discharge Date

Note: The discharge date is from the acute care hospital, which should be consistent with the date obtained by the abstractors from the hospital's medical records. It is not the date of discharge from a rehabilitation facility.

## PAI-08c: Receive Rehabilitation

Note 1: The participant may refer to rehabilitation as "rehab."

Note 2: More than one response is allowed for the different facilities the participant may have received services.

PAI-08d: Inpatient or Outpatient Rehabilitation

Prompt: If the participant asks what is inpatient rehabilitation, state, "Inpatient rehabilitation means that you spent at least one night at a rehabilitation facility to receive health care services from a physician, nurse or therapist who works there."

Prompt: If the participant asks for a definition of outpatient rehabilitation, state, "Outpatient rehabilitation means that you received services from a physician, nurse, psychologist or therapist without spending the night in a hospital to receive those services."

Notes: If the participant asks if outpatient rehabilitation is the same as ambulatory services, the answer is "yes."

It does not matter at which facility participants receive either type of rehabilitation.

## PAI-09 Caregiver Burden

Purpose: Document family changes since the injury.

Includes: Not taking a new job.

Notes: Responses like "If I had not been retired already, I would have had to do so" cannot be counted as quitting a job.

For any annual interview, the time reference remains "Since your injury."

## PAI-10 Problems hearing on the phone

Instructions: Use this question to help determine if the participant needs a proxy because of a hearing problem. If respondent responds with a generic answer about hearing problems, speak a bit more loudly and ask "Can you hear me now?" If the respondent still has trouble hearing, determine if a proxy is needed. If the problem is due to a faulty telephone connection, explain to the participant or proxy that you plan to hang up and re-dial.

MULTIPLE CONCUSSIONS

Purpose: To determine history of loss of consciousness due to brain **injury**.

MCC- 01 Concussion since injury

Probe: “Knocked out or unconscious means any time you’ve lost consciousness or blacked out, even if it was only for a few seconds.”

Excludes: Fainting or seizure

MCC-02 Concussion after injury

Probe: “Knocked out or unconscious means any time you’ve lost consciousness or blacked out, even if it was only for a few seconds.”

Excludes: Fainting or seizure

PRE-EXISTING CONDITIONS

Purpose: To determine history of pre-injury health conditions/medication use.

Rule: Read the first **three** complete questions and then read just the health condition unless you feel the respondent needs the complete question read each time.

Note: Although the question asks “did a doctor tell you?,” record the response as yes if the respondent reports that a nurse or another healthcare professional, such as a physician’s assistant, told them they had the condition.

PEC-01 Stroke before injury

Includes: CVD (Cerebrovascular disease) or CVA (cerebrovascular accident)

Excludes: TIA (transient ischemic attack)

Probe: “If you do not know what it is, chances are you have not been told that you had it,” then repeat the question.

PEC-02 Epilepsy or seizure before injury

Probe: Some people may call it “convulsion,” “fit”, “falling out spell”, “episode”, “attack”, “drop attack”, “staring spell”, or “out-of-touch.”

PEC-03 Mood medicine before

Includes: medicine for anxiety, depression, schizophrenia, and other “nerve problems.”

Note: If the respondent gives the name of a medicine and does not know what it is used for, write down the name and fill out a Decision Log form after the interview.

PEC-05 Psychiatric disorder before injury

Includes: Schizophrenia; dementia; Alzheimer’s Disease; anxiety disorder, which includes post-traumatic stress disorder (from another injury); depression; nervous breakdown; and “nerve problems.” Many people refer to psychiatric disorder (illness) only as “nerve problems.”

Excludes: Attention deficit disorder

PEC-06 Drug or alcohol problem before injury

Includes: Having been to Alcoholics Anonymous (AA) at any time in the past

## LIFE SATISFACTION

Purpose: To determine how the respondent feels about his/her life.

Notes: Do not ask the proxy the questions in this section.

The time reference for these questions is **now**.

Due to the difficulty level of the 7 response options, it may be necessary to repeat them after each statement.

LIS-01 Life close to ideal

Definition: "It's what you would imagine to be perfect or as good as you would want it to be."

GENERAL HEALTH

- Purpose:
1. To determine the current overall health status and outcomes, including general mental health and functional status, from the respondent=s point of view.
  2. To be able to compare with population norms and results of studies of other disabling conditions.

Rule: If the respondent has difficulty responding, repeat the question verbatim.

Notes: Due to the difficulty level of the response options, it may be necessary to repeat them more than once. Respondents should be encouraged to answer based on what they think the question means.

Any physical impairment or disabling condition such as blindness can be considered a component of general health.

When administering the proxy version, be aware that the questions have been changed to reflect the proxy=s opinion.

Example: “In general would you say his (or her) health is .....

Definition(s):

Health - anything related to your health, not just your injury.

Limited a lot - includes not being able to do.

GEH-02 General health-compared to before injury

Definition(s):

Before injury – “before [injury date].”

GEH-03 - GEH-12

Coding: When the subsequent question “Is that because of your health?” is asked, and respondent responds “yes” they do not do activity because of their health, code 1=limited a lot. If they respond no they do not do activity but not because of their health, code 3=not limited at all.

GEH-06 Climbing several flights of stairs

Probe: "A flight of stairs is 10 steps."

GEH-07 Climbing one flight of stairs

Probe: "climbing a flight of stairs means going up 10 steps without resting"

Probe: If respondent states that the preceding response should have answered this question, respond: "We have to ask all of the questions."

GEH-08 Bending, kneeling, or stooping

Coding: A limitation in any one or more counts as a positive response. Code 1 or 2.

GEH-10 Walking several blocks

Probe: If respondent says that the preceding response should have answered this question, respond: "We have to ask all of the questions."

GEH-11 Walking one block

Probe: If respondent says that the preceding response should have answered this question, respond: "We have to ask all of the questions."

GEH-21 Pain interfere

Clarification: Pain includes both bodily pain and emotional pain.

GEH-22 Bodily pain

Probe: "Bodily pain is pain in any part of your body, including headaches."

GEH-24 through GEH-32

Note: These questions have 6 response choices, be prepared to repeat the responses several times.

GEH-24 How much time full of pep

Probe1: "Full of pep" means that you feel very **peppy**.  
Probe2: "Pep" means that you feel lively or have vigor.

GEH-25 Been a nervous person

Excludes: Parkinson=s disease and neurological conditions which cause a body part to shake.

GEH-30 How much time feel worn out

Probe: "It means how much time you just feel really **worn down**."

GEH-35 Expect health to get worse

Probe if respondent questions the time frame for health to get worse: "In general do you expect your health to get worse?"

ALCOHOL AND DRUG ASSESSMENT

Purpose: To determine current and pre-injury alcohol consumption and drug use

Note: May be a sensitive topic for respondents, especially those who do not consume alcohol OR those who drink a lot.

Definition(s):

Week - Number of days you drank out of 7 days.

Month - Number of days you drank out of 30/31 days.

DRA-02 Days drank in past month

Coding: Enter either the number of days per week (1-7) **OR** the number of days per month (1-31).

DRA-03 Number of drinks

Definition(s):

Bottle or can of beer - 8 ounces is **one** drink.

Quart of beer - 32 ounces is **four** drinks.

Shot of liquor - 1 ounce is **one** drink.

Fifth of liquor - **13** (1 oz.) drinks

Glass of wine - 4 to 5 ounces is **one** drink.

Bottle or can of wine cooler - 10 ounces is **one** drink.

Note: If response given is a range such as 4 to 8 -

Probe: “You just told me you had 4 to 8 drinks, can you give me one number for your usual number of drinks?”

If the respondent still cannot be definitive, code using the average of the two numbers.

DRA-04 Times had 5 or more drinks

Note: If response is inconsistent with DRA-03—

Probe: “You just told me you have [DRA-03 response]. Is it [ DRA-3 response] OR [DRA-04 response] drinks?”

DRA-06 Illegal drug use since injury

Probe: “An illegal drug is one that it is against the law to have or to take.”

DRA-07 Excludes: Prescription medicine or prescription medicine prescribed for another person.  
Illegal drug use before injury

Note: If respondent reports in DRA-06 that “has never used illegal drugs,” record as 2=No.

SERVICE NEEDS - ALCOHOL AND DRUG TREATMENT

Purpose: To determine whether participants have received drug and alcohol services after injury; whether they feel they need each service at the time of the interview; and if they need it, why haven't they received it.

Notes: Do not ask these questions of respondents who report no pre- or post-injury alcohol or drug use.

For all service needs questions except SDN-07, help can come from anyone paid or unpaid, e.g., a friend, family member, or agency personnel. For SDN-07, help MUST be paid help.

SDN-01 Received help controlling alcohol or drug use

Includes: going to Alcoholics Anonymous (AA)

SDN-01b Reason not received

Instructions: Read question and pause for answer. If the respondent spontaneously responds, record their answer verbatim. Match this answer to one of the existing response options. If the response can not be coded promptly using existing categories, record as "9=any other reason." If the respondent does not answer, read the choices slowly and allow only one main reason.

After the response, clarify with, "So the **main** reason you have not received help is [repeat the response]."

POST-INJURY SYMPTOMS

Purpose: To determine whether the respondent is experiencing symptoms that are common after a brain injury and whether they impact on their current abilities.

Instructions: Remember to emphasize “**during the past 4 weeks.**”

Note: If a physician or another healthcare professional told a reliable person such as the parent that the participant had the condition, code as having it.

PIS-01 Vision

Definition(s):

Vision - Difficulty seeing that interferes with being able to do daily activities. For people who wear glasses this means having this difficulty when they are wearing their glasses.

Includes: “seeing double.”

PIS-02 Paralysis in arms or legs

Definition(s):

Paralysis means you've lost feeling or cannot voluntarily move part of your body.”

Includes: "partial" paralysis, i.e., they still have some feeling or can move, but ability is reduced

Excludes: difficulty moving due to pain only.

PIS-03 Epilepsy or seizure disorder

Probe: Some people may call it “convulsion,” “fit,” “falling out spell,” “episode,” “attack,” “drop attack,” “staring spell,” or “out-of-touch.”

PIS-03e: Treatment interfered

Examples: “Normal activities like working, going to school, or socializing with family or friends”

PIS-04 Hearing

Note: If respondent reports conditions in ear other than hearing loss such as ringing in the ears—

Probe: “Does [condition] cause trouble with your hearing?”

PIS-06                      Trouble sleeping

Includes: needing more sleep, more trouble falling asleep, waking up during the night, waking up too early and not being able to fall asleep again, sleeping more or “too much.”

Clarification: If the participant reports that he or she uses a medication to help with sleep problems, although the person can now sleep, code the response as having the problem.

PIS-07                      Tense or keyed up

Probe: “It means you feel anxious”

PIS-11 to PIS-13

Note: Changes time reference to “since your injury.”

PIS-11                      Mood Medication

Includes: medication for depression

Note: If respondent gives the name of a medication and does not know if it is a medication for mood, write it down and fill out a decision log form after the interview

PIS-13                      Psychiatric disorder after injury

Includes: Personality and mood disorders, schizophrenia, post-traumatic stress disorder, dementia, Alzheimer’s Disease, anxiety disorder, depression and “nerve problems,” and medications or counseling for those problems. Many people refer to psychiatric disorder (illness) only as “nerve problems.”

Excludes: Attention deficit disorder

VIOLENCE SCREEN - PERPETRATOR

Purpose: To determine perpetration of violence by respondent after brain injury.

Note: Do not ask this question of the proxy.

VIO-01 Respondent hit, kicked, punched, or physically hurt anyone

Excludes: Military or sports activities; wrestling or playing around with friends;  
persons injured in the line of duty such such as police or corrections officers

Probe: “Since your injury, have you purposely tried to physically hurt someone?”

COGNITION

Purpose: To determine if the respondent is having difficulties with thinking, remembering, problem-solving, and other cognitive abilities.

Coding: Even if a respondent reports that the problem is due to medication, code as having the problem.

COG-02 More minor accidents

Clarification: More— “more than usual.”

COG-05 Difficulty solving problems

Note: If respondent does not understand the question, repeat the question and **emphasize** the examples in the question.

COG-06 Confused or disoriented: person, place, time

Note: If respondent does not understand the question, repeat the question and **emphasize** the examples in the question.

COG-09 More mistakes than usual

Probe: “Usual” means expected.

SELF-RATED DISABILITY

Purpose: To determine the respondents' perception of whether or not they have a disability.

Note: Do not ask this question of the proxy.

SRD-01 Consider yourself to have a disability

Probe: "It is whatever you think disability means."

Clarification: Disability can be emotional or physical.

EMPLOYMENT

Purpose: To determine current work status and changes since the injury, including the need for help in working

Includes: Receiving any amount of pay, being paid “under the table” (paying job).

EPW-01 Hours currently working

Probe: “Are you working at the present time?”  
 If yes,  
 “Do you get paid for the work you are doing?”  
 If yes, ask number of hours.  
 If no, go to “Not working.”

Note: If respondent reports hours worked as a range that exceeds 40 hours, use the following probe.

Probe: “On the average, how many hours per week do you work? Please give me your best guess.”

NOT WORKING

EPN-01 Retired

Definition(s):

Retired - Respondent has stopped working and does not intend to go back to work on a full-time, **permanent** basis to the job from which he or she retired.

Note: A respondent could be retired and receiving disability income and/or workers’ compensation during the same time period.

Probe: “Have you stopped working without planning to go back to work at that job on a full-time, permanent basis?”

EPN-01b Retire because of injury?

Please note that 2=No, “Specify reason” is the appropriate place to record a response of person retired due to “reached retirement age” if the respondent offers a response.

EPN-01c Receiving workers’ compensation income?

Definition: Workers' compensation is paid to persons injured while performing the essential functions of their jobs. It is intended to provide income until they can return to work. A person can receive both disability income and workers' compensation at the same time. In addition, an individual who is eligible for workers' compensation will probably be entitled to receive a settlement. This settlement could greatly impact the person's total income for that year.

EPN-02            How many paying jobs?

Note: For the annual interview participants may have difficulty with the time reference "Since the last time we talked with you." Therefore, repeat the date of the last interview.

EPN-01e        Receiving disability income?

Definition: Disability income is paid to people who previously worked, but currently have chronic health conditions that prevent them from working.

Social Security Disability Income (SSDI) is a federal program under Medicare, which is often paid to persons less than 65 years old who have long-term disabilities that prevent them from working. It is not dependent upon having previously worked.

EPN-06            Main reason not working

Note: To encourage a response, use the transitional phrase, "We understand that there are many reasons people don't work."

After the response, clarify with, "So the **main** reason you're not working is [repeat the response]."

EPN-07            Lose benefits if working

Includes: Medicaid, Social Security Disability Insurance (SSDI), and/or Workers' Compensation

Probe: "Would you lose benefits if you were working EITHER full or part time?"

EPN-09            Job title before injury

Probe: "What type of job did you do before your injury?"

Examples: electrician, supervisor, mechanic, teacher, truck driver, plumber, writer, nurse, housekeeper.

SERVICE NEEDS - EMPLOYMENT: NOT WORKING

**Purpose:** To determine if help with finding employment, improving job skills, and finding places and opportunities to socialize was received; if participant thinks help is needed at the time of the interview; and if needed and none received, why not.

For all service needs questions except SDN-07, help can come from anyone paid or unpaid, e.g., a friend, family member, or agency personnel. However, for SDN-07, help **MUST** be paid help.

**Definition:** Service—professional help with a service need.

**SDN-02** Helping finding paid employment - received

**Clarification:** Help finding paid employment—Someone helped you find work.

**SDN-03** Improving job skills - received

**Definition(s):** “Help improving job skills means any training or classes to help you get or keep a job.”

**Includes:** Job site modifications or job coaching in order to get or keep a job.

**SDN-03a** Help improving job skills - needed

**Includes :** Any training or classes they think would help them get or keep a job, including cognitive retraining.

**SDN-03b** Reason not received

**Instructions:** Read question and pause for answer. If the respondent spontaneously responds, record their answer verbatim. Match this answer to one of the existing response options. If the response can not be coded promptly using existing categories, record as “9=any other reason.” If the respondent does not answer, read the choices slowly and allow only one main reason.

**Note:** After the response, clarify with, “So the **main** reason you have not received help is [repeat the response].”

SDN-04b Opportunities to socialized - Reason not received

Instructions: Read question and pause for answer. If the respondent spontaneously responds, record their answer verbatim. Match this answer to one of the existing response options. If the response can not be coded promptly using existing categories, record as “9=any other reason.” If the respondent does not answer, read the choices slowly and allow only one main reason.

Note: After the response, clarify with, “So the **main** reason you have not received help is [repeat the response].”

EMPLOYMENT- WORKING

EPW-02            How many paying jobs?

Note: For the annual interview participants may have difficult with the time reference “Since the last time we talked with you.” Therefore, repeat the date of the last interview.

EPW-03            Current job title

Probe:            “What type of job do you have now?”

Example: electrician, supervisor, mechanic, teacher, truck driver, plumber, writer, nurse, housekeeper.

EPW-05            Job title before injury

Probe:            “What type of job did you do before your injury?”

Example: electrician, supervisor, mechanic, teacher, truck driver, plumber, writer, nurse, housekeeper.

EPW-07            Limited now in number of hours can work

Clarification: Since the question is intended to capture limitations due to health problems, attending school should not be misinterpreted as a reason for coding the response as limited in the number of hours they can work if they otherwise report no health problems.

EPW-09            Difficulties at work

Coding:           Each letter needs a response of either 1, 2, 777, or 888.

Do not read f. as a response option. Code f. “yes” if response is no to a.-e.

SERVICE NEEDS - EMPLOYMENT: WORKING

**Purpose:** To determine if help with finding employment, improving job skills, or finding places and opportunities to socialize was received and if none received, why not.

**Note:** For all service needs questions except SDN-07, help can come from anyone paid or unpaid, e.g., a friend, family member, or agency personnel. For SDN-07, help **MUST** be paid help.

**SDN-05** Improving job skills - received

**Definition(s):** “Help improving job skills means any training or classes to help you get or keep a job.”

**Includes:** Job site modifications or job coaching in order to get or keep a job.

**SDN-05a** Help improving job skills - needed

**Includes:** Any training or classes they think would help them get or keep a job, including cognitive retraining.

**SDN-05b** Reason not received

**Instructions:** Read question and pause for answer. If the respondent spontaneously responds, record their answer verbatim. Match this answer to one of the existing response options. If the response can not be coded promptly using existing categories, record as “9=any other reason.” If the respondent does not answer, read the choices slowly and allow only one main reason.

**Note:** After the response, clarify with, “So the **main** reason you have not received help is [repeat the response

SDN-06b Opportunities to socialize - Reason not received

**Instructions:** Read question and pause for answer. If the respondent spontaneously responds, record their answer verbatim. Match this answer to one of the existing response options. If the response can not be coded promptly using existing categories, record as “9=any other reason.” If the respondent does not answer, read the choices slowly and allow only one main reason.

**Note:** After the response, clarify with, “So the **main** reason you have not received help is [repeat the response].”

ACTIVITIES OF DAILY LIVING

**Purpose:** To determine whether the respondent has difficulty or needs help or supervision when performing a range of daily activities.

**Definition(s):**

Supervision - Someone is home in case you need help with a specific activity or to ensure safety.

Special Equipment - Being able to do the activity without using special equipment means without using devices that help the participant do the activity. [Sometimes they are called assistive devices, assistive technology, or assistive equipment.]

Examples: shower chairs or benches, transfer boards, special handled spoons or forks, special cups, wheelchairs, walking sticks, prosthetics, braces, special commode seats, grab bars, hand rails, ramps, guide dogs.

**Note:** The lay public often use the term “rolling chair” as a synonym for wheelchair.

**Note:** Any physical impairment or disabling condition such as blindness could greatly impact ADL responses. Remember to comment about the condition after the interview under INT-02.

**General Probe to Determine Help or Supervision:**

Probe1: “ Do you have someone in the house with you in case you need help?”

**Notes:** If it is reported that another person stays with the participant during the day, determine whether that person helps or supervises the participant with ADLs.

If the participant needs help or supervision intermittently, code as needing help or supervision.

If the participant needs help or supervision, but is not receiving it, code as needing help or supervision.

ADL-01 Bathing and showering

**Probe:** “Are you able to take a bath or shower by yourself?”

ADL-01b Supervise while Bathing or Showering

Clarification: “Someone who supervises you is with you at least part of the time in case you need help with bathing or showering.”

ADL-02b Supervise while Dressing

Clarification: “Someone who is in the house with you in case if you need help with dressing yourself.”

ADL-03 Eating

Clarification: “Eating includes feeding yourself, cutting food, holding a fork, or drinking from a glass.”

ADL-03b Supervise while Eating

Clarification: “Someone who supervises you is with you at least part of the time in case if you need help with eating.”

ADL-04b Supervise while getting in and out of bed or chairs

Clarification: “Someone who supervises you is with you at least part of the time in case if you need help with getting in and out of bed or chairs.”

ADL-05b Supervise while walking

Clarification: “Someone who supervises you is with you at least part of the time in case if you need help with walking.”

Definition: How much difficulty they have walking refers to the basic skill as they would do in a small room.

ADL-05c Special equipment

Definition(s): Special equipment - refers to walkers, wheelchairs, scooters, braces, crutches, canes.

ADL-06b Supervise while using toilet

Clarification: “Someone who supervises you is with you at least part of the time in case if you need help with using the toilet.”

VIOLENCE SCREENER - NEGLECT

Purpose: To determine if person feels neglected by caregiver in the home.

Note: Do not ask this question of the proxy.

VIO-02 Neglected since injury

Probe: “Do you have someone who usually takes care of you? [If no, record “no” and skip to next question.]

INSTRUMENTAL ACTIVITIES OF DAILY LIVING

Purpose: To determine respondent's ability to perform higher level daily activities.

Definition(s): Supervision - Someone spends at least part of the time in the room with participant to see if individual is safe or can do a specific activity.

IAD-01a Supervise while preparing meals

Clarification: "Someone who supervises you is with you for at least part of the time in case you need help."

IAD-02a Supervise while shopping for groceries or personal items.

Note: Does not include getting to the store.

Clarification: "Someone who supervises you is with you for at least part of the time in case you need help."

IAD-02b Someone regularly does

Probe: "Regularly means most of the time."

IAD-03 Managing money

Probe: Repeat "Such as keeping track of expenses or paying bills."

IAD-03a Supervise

Clarification: "Someone who supervises you is with you for at least part of the time in case you need help."

IAD-03b Someone regularly does

Clarification: "Regularly means most of the time."

IAD-04 Someone supervised or did the activity before injury

Probe: "Before your injury, were you able to [indicate one activity: prepare meals, shop, manage money] by yourself?"

Clarification: “Someone who supervises you is with you for at least part of the time in case you needed help.”

SERVICE NEEDS - PERSONAL ASSISTANT/PERSONAL CARE ATTENDANT

Purpose: To determine the need for help from a person or equipment to do daily activities.

Includes: paid help

Excludes: help that may come from family members, etc., unless paid

For all service needs questions except SDN-07, help can come from anyone paid or unpaid, e.g., a friend, family member, or agency personnel. For SDN-07, help **MUST** be paid help.

SDN-07 Personal assistant/personal care attendant - received

Definition(s): Receiving help or supervision to do (or learn to do) any one or more of the following as independently as possible— bathing, dressing, getting to/from chair or bed, eating, going to the toilet, shopping, preparing meals, managing money—from a **PAID** person who comes to your home. In most instances, the attendant remains with the participant for long periods of time and often lives with the participant.

Includes: help learning to use public transportation  
help learning to use memory aids

Excludes: care provided by a nurse or other medical provider in the home  
therapies such as OT, PT, Speech, even if they focus on functional tasks, including assistive technologies such as communication devices  
help to people who live in nursing homes  
help at work  
transportation that is provided to the person  
housecleaning performed by the person  
home maintenance/modification  
respite care/paid companion

SDN-07b Reason not received

Instructions: Read question and pause for answer. If the respondent spontaneously responds, record their answer verbatim. Match this answer to one of the existing response options. If the response can not be coded promptly using existing categories, record as “9=any other reason.” If the respondent does not answer, read the choices slowly and allow only one main reason.

Note: After the response, clarify with, “So the **main** reason you have not received help is [repeat the response].”

## MARITAL STATUS AND LIVING SITUATION

**Purpose:** To determine who lives with the respondent, and if the respondent is married and where they live, including changes since injury.

**Note:** Living in an assistive living facility is considered living “with residents of special housing.”

Living in a retirement community is considered living in a private residence.

**MAS-01 Clarifications:** “Never been married” excludes “members of an unmarried couple.”

The intent of the response “A member of an unmarried couple” is to identify couples who are in a relationship.

**Note:** If more than one response is given, code only the one response in the time period most close to “before the injury.”

**MAS-02 Clarifications:** “Never been married” excludes “members of an unmarried couple.”

The intent of the response “A member of an unmarried couple” is to identify couples who are in a relationship.

**Note:** If more than one response is given, code only the response that is the status today.

SERVICE NEEDS - INCREASING INDEPENDENCE

Purpose: To determine whether the respondent feels they need help to live more independently.

Instructions: Read question and pause for spontaneous answer. If no response, read choices slowly.

For all service needs questions except SDN-07, help can come from anyone paid or unpaid, e.g., a friend, family member, or agency personnel. For SDN-07, help **MUST** be paid help.

SDN-08 Increasing independence in housekeeping, cooking, shopping- received

Probe: “It means help to learn how to do any of these activities on your own as much as possible.”

SDN-08b Reason not received

Instructions: Read question and pause for answer. If the respondent spontaneously responds, record their answer verbatim. Match this answer to one of the existing response options. If the response can not be coded promptly using existing categories, record as “9=any other reason.” If the respondent does not answer, read the choices slowly and allow only one main reason.

Note: After the response, clarify with, “So the **main** reason you have not received help is [repeat the response].”

SOCIAL INTEGRATION

Purpose: To determine if the respondent engages in routine social activities.

Note: For these two questions, if the participant resides in a nursing home, substitute “your **nursing** home” for “your home.”

SOI-01 Socialize in home

Probe: “Do friends or relatives come to visit you?”

SOI-02 Socialize outside of home

Probe: “Do you go out and do things with other people?”

SOCIAL SUPPORT

Purpose: To determine the perceived likelihood of various types of practical support being available to the respondent.

SERVICE NEEDS - INFORMATION, CASE COORDINATION, MENTAL HEALTH

**Purpose:** To determine whether the respondent has received or needs information or help to obtain services or mental health treatment.

**Instructions:** Read question and pause for spontaneous answer. If no response read choices slowly.

For all service needs questions except SDN-07, help can come from anyone paid or unpaid, e.g., a friend, family member, or agency personnel. For SDN-07, help **MUST** be paid help.

## SDN-09b Information about services - Reason not received

**Instructions:** Read question and pause for answer. If the respondent spontaneously responds, record their answer verbatim. Match this answer to one of the existing response options. If the response cannot be coded promptly using existing categories, record as “9=any other reason.” If the respondent does not answer, read the choices slowly and allow only one main reason.

**Note:** After the response, clarify with, “So the **main** reason you have not received help is [repeat the response].”

Examples of possible services:

1. controlling alcohol and/or drug use
2. finding paid employment
3. improving your job skills
4. finding places and opportunities to socialize with others
5. obtaining help from a paid personal assistant or personal care attendant
6. increasing your independence in housekeeping, cooking or shopping
7. receiving information about services that may be available to you
8. receiving help getting and managing the services you receive
9. improving your mood, managing stress or emotional upsets
10. traveling to places in your community

**NOTE:** Skip SDN-10 if the respondent reports no services needed.

For all service needs questions except SDN-07, help can come from anyone paid or unpaid, e.g., a friend, family member, or agency personnel. For SDN-07, help **MUST** be paid help.

SDN-10 Help coordinating services - received

Clarification: “Coordinating services means that someone helps you get services or helps to manage them.”

SDN-10b Reason not received

Instructions: Read question and pause for answer. If the respondent spontaneously responds, record their answer verbatim. Match this answer to one of the existing response options. If the response can not be coded promptly using existing categories, record as “9=any other reason.” If the respondent does not answer, read the choices slowly and allow only one main reason.

Note: After the response, clarify with, “So the **main** reason you have not received help is [repeat the response].”

SDN-11 Help with improving mood, managing stress or emotional upsets - received

Includes: AA, counseling, psychotherapy, help from family or friends  
Excludes: medication

For all service needs questions except SDN-07, help can come from anyone paid or unpaid, e.g., a friend, family member, or agency personnel. For SDN-07, help **MUST** be paid help.

SDN-11b Reason not received

Instructions: Read question and pause for answer. If the respondent spontaneously responds, record their answer verbatim. Match this answer to one of the existing response options. If the response can not be coded promptly using existing categories, record as “9=any other reason.” If the respondent does not answer, read the choices slowly and allow only **one** main reason.

Note: After the response, clarify with, “So the **main** reason you have not received help is [repeat the response].”

VIOLENCE SCREEN - PHYSICAL AND SEXUAL ABUSE

Purpose: To screen for experience with physical violence/abuse and sexual violence/abuse.

Note: Do not ask these questions of the proxy.

VIO-03 Respondent physically hurt

Probe: “Since your injury, has someone purposely tried to physically hurt you?”

Excludes: Military or sports activities; playful wrestling with friends or family members; persons injured in the line of duty such as police or corrections officers

VIO-04 Sexual abuse

Probe: “We mean someone touching your private parts, making you touch their private parts or having sexual intercourse without your consent.”

Includes: Unwanted touching of private body parts, being forced to touch someone else’s private parts, fondling, forcing one to take off their clothes, inserting objects or fingers vaginally or anally, sexual intercourse.

TRANSPORTATION

Purpose: To determine transportation needs and changes since the injury.

TRN-01 Method of transportation

Instructions: Allow only one choice.

SERVICE NEEDS - TRAVELING

Purpose: To determine if respondent has transportation needs

SDN-12 Getting to places in the community - received

For all service needs questions except SDN-07, help can come from anyone paid or unpaid, e.g., a friend, family member, or agency personnel. For SDN-07, help **MUST** be paid help.

SDN-12b Reason not received

Instructions: Read question and pause for answer. If the respondent spontaneously responds, record their answer verbatim. Match this answer to one of the existing response options. If the response can not be coded promptly using existing categories, record as "9=any other reason." If the respondent does not answer, read the choices slowly and allow only one main reason.

Note: After the response, clarify with, "So the **main** reason you have not received help is [repeat the response]."

INSURANCE

Purpose: To document whether the respondent's health insurance status has changed since injury.

INS-01 Have health care coverage

INS-01a Main reason no health care coverage

Instructions: Allow only one main reason.

Note: After the response, clarify with, "So the **main** reason you have no health care coverage is [repeat the response]?"

INS-01s Specify

Instructions: Record response.

INS-02a Medicaid

Probe: "If you don't know the name, chances are you are not covered by Medicaid."

INS-02b Medicare

Probe: "If you don't know the name, chances are you are not covered by Medicare."

INS-02c HMO (Health Management Organization) PPO (Paid Provider organization)

Instructions: If the individual reports a name of an insurance company, yet does not know if it is an HMO or private insurance, code 888=Don't Know.

INS-02d Private insurance

Instructions: If the individual reports a name of an insurance company, yet does not know if it is an HMO or private insurance, code 888=Don't Know.

INS-02e Champus, Tricare, or Veterans (VA)

Probe: "This is insurance for people who are in the military"

INS-03 Postponed health care

Clarification: "Since your injury, have you ever not gotten health care you felt you needed because you did not have insurance?"

Note: Healthcare includes dental care and mental health.

EDUCATION

Purpose: To document the participant's educational history

## EDU-01 Highest grade before injury

Note: If age 69 years or older and response is 3, clarify if completed high school or high school was only 11 grades. (This was the case in South Carolina until 1948.) If high school was only 11 grades, code 4.

Further clarification may be needed as to whether to code 3 or 4 if the response is technical school. (A student can enroll in technical school both during and after high school.) If technical school was part of high school, consider each year as a year of high school; if attended technical school after high school, code technical school as additional schooling (below)

Probe: If had extra training since high school, "How much extra training did you have? Was it at least one year?"

## EDU-02 Classes since discharge from hospital

Definitions: Class or classes can be from a wide variety of curricula, including those taken as part of home school, technical school, cooking classes, employment training, classes offered by your employer, or web courses on the computer.

Technical school is a school you attend for usually two years or less to learn a particular skill or trade such as plumbing, electrical, nursing, dental assistance, manufacturing, heating and air conditioning.

## EDU-02a Graduated or earned a degree

Instructions: Record unclear responses under "Specify" and code later.

Note: This question focuses on completing major educational milestones. If the educational milestone in the list of responses has not been reached, record at the lower level.

## EDU-03s Specify

Instructions: Record response

INCOME

Purpose: To determine the respondent's personal income, including any changes since the injury.

Note: Reported income is limited to the amount of income people are willing to report.

INC-01 Total personal income after injury

Probe: "What should I write down for your income?"

Clarification: If participant states has no income, record #4=below \$10,000.

INC-01a If income is reported on a bi-weekly basis, please indicate bi-weekly income as #4, calculate, and record under INC-01b.

Probe to clarify that the respondent's answer is valid: "Is this the amount before taxes?"

We still may not capture all deducted income ie monies paid for health insurance, stock options etc. but as you explained yesterday we should not be concerned with this. I just wanted to point it out.

INC-02 Income disability or workers' compensation payments

Definition: Disability income is paid to people who previously worked, but currently have chronic health conditions that prevent them from working.

Social Security Disability Income (SSDI) is a federal program under Medicare, which is often paid to persons less than 65 years old who have long-term disabilities that prevent them from working. It is not dependent upon having previously worked.

Definition: Workers' compensation is paid to persons injured while performing the essential functions of their jobs. It is intended to provide income until they can return to work. A person can receive both disability income and workers' compensation at the same time. In addition, an individual who is eligible for workers' compensation will probably be entitled to receive a settlement. This settlement could greatly impact the person's total income for that year.

INC-03 Total personal income before injury

Probe: "What should I write down for your income?"

INC-03a If income can only be reported as annual income, divided by 12 to calculate the response as monthly.

INC-04 Main person family or household depends on

Note: Providing the majority of household income constitutes being the main person.

SERVICE NEEDS - 1 MOST IMPORTANT

Purpose: To document unmet service needs.

SDN-13 One most important need

SDN-13a Instructions: Ask this question of those respondents who report at least two needs in the previous SDN questions.

IMPORTANT THAT THEY CHOSE ONLY 1 ANSWER AND IF ALL ARE EQUALLY IMPORTANT, A NOTE CAN BE ADDED TO THE NEXT QUESTION.

SDN-14 Important need not asked

Instructions: Ask this question of all respondents.

SPIRITUALITY

Definition: “Spiritual means belief in a supreme being.”

PARTICIPANT CONTACT INFORMATION

CON-06 Phone number including area code

Instructions: Make sure to ask for area code if one is not reported.

CON-12 Phone number including area code

Instructions: Make sure to ask for area code if one is not reported.

## INTERVIEW INFORMATION

INI-09 Ending time

Instructions: Ending time will be automatically recorded if data are collected by direct computer entry.

INI-10 Total interview time

Instructions: Total time will be automatically recorded if data are collected by direct computer entry.

INI-13 Requested Interview Information

Instructions: If respondent requests a copy of the interview at any time during the interview, record as “yes.” Do not ask respondent if they would like to receive information.

## INTERVIEWER INFORMATION

INT-02 Information specific to participant

Note: Record any important information about the participant that was mentioned during the course of the interview such as other disabling conditions present either after the injury or those that were pre-existing.

Examples: spinal cord injury, Alzheimer’s disease, mental retardation, stroke, spina bifida, Parkinson’s disease, amputation, blindness, arthritis, etc.

## DECISION LOG PROTOCOL

### Using the SCTBIFR Decision Log to Document Problems with Questionnaire Items

Adapted from the CDC Study to Assess Falls Among the Elderly (SAFE)

**Purpose:** To document problems encountered in interviewing, to resolve these problems in a standardized way, and to correct and re-enter data when necessary so that responses are coded consistently.

**Definition:** An interviewing problem includes:

- (a) any item for which the interviewer perceives a need to deviate (even a little) from the actual wording of the question as it is written on the questionnaire to facilitate a response,
- (b) any question for which an accurate code for the response given by the respondent is not available among the choices on the questionnaire,
- (c) any other issue that arises during the interview.

**Instructions:**

6. Interviewers are to write down a description of ANY PROBLEM related to administration of a specific question. These descriptions, including the question item code, are to be recorded during or immediately following the interview on the appropriate form. See Decision Log e-form located in Appendix A.
1. The lead interviewer will send these logs electronically to the scientific advisory team who will make a determination as to the best solutions to the problems. Logs will be filled out and returned via email. The scientific advisors are the principal investigator, the CDC technical officer, and the co-investigator for research and follow-up. Decisions will be recorded and reviewed with the interviewers on a monthly basis unless interviewers request a more frequent review.
3. If necessary, the initial data entry for that specific question (and others if other interviewers experienced the same problem) will be changed to conform to the solution.
4. All Decision Log sheets and their solutions are to be maintained in a centralized notebook organized by question number. This is to serve as a key reference for confirming previous determinations. Additional interviews with the same problem are to be referenced by listing the ID number for that interview in the list at the bottom of the log sheet for that problem. Notebook entries also will serve to document systematically the need to consider changes to the questionnaire including refining lead-ins or definitions, providing standardized alternatives to the question wording.

## SCTBIFR ELECTRONIC DECISION LOG

Question No.:  
 Page Number:  
 Participant ID No.:  
 Interview Date:  
 Interviewer's Initials:

1. Complete demographical information.
2. Describe the problem.
3. Report how questions was coded.
4. IDs with similar problems may be recorded on the same sheet.
5. Put this sheet in the front of the Decision Log notebook.
6. Decisions will be rendered by the Scientific Advisors, reviewed with interviewers by Project Coordinator, and incorporated into the Questionnaire Manual for future use.

<b>Description of the Problem:</b>	<b>Interviewer coded as:</b>

Other IDs with same/ similar problem	Interview Date	Coded as	Interviewer Initials

Send Date	Decision Rendered by Scientific Advisors	Scientific Advisor Initials	Return Date

Date Discussed with interviewers	Summary of Action Taken	re-code as

## CRISIS PROTOCOL

The SCTBIFR is committed to providing assistance to interview respondents, as appropriate, in circumstances assessed as being emergent or urgent/serious medical, safety or psychological situations. In order for interviewers to be prepared to handle such situations, a crisis intervention training session will be incorporated into the interviewers overall training protocol. In short, three types of crisis situations (defined below) can occur on two severity levels.

Medical - medically related problem such as stops responding, distress sounds etc.

Physical - assault or bodily harm

Psychological - signs and/or symptoms of depression or other mood problem

The two severity levels are (1) emergency and (2) urgent/serious. Emergency situations are when the threat is imminent. It could be a threat to self or others, e.g., respondent threatens immediate suicide or homicide require. Emergency situations require immediate action by the interviewer. Action regarding urgent/serious situations can be delayed for 24 hours or more. The respondent is not in immediate danger but is a risk of having a serious problem in one of the above areas.

Handling Emergency Situations. During the course of an interview, if the interviewer suspects that an medical, physical, or psychological emergency may be occurring or imminent, the interviewer should follow emergency steps A-I-D as shown in the box above. Emergency incidents should be reported within 24 hours to the Data Manager using the SCTBIFR Emergency Report form. The data manager will pursue the appropriate follow-up action.

# A - I - D

**A s s e s s**

VIOLENCE / NEGLECT / MEDICAL

U **Imminence**  
 “Do you need for me to call someone to help you now?”  
 If yes, “I am going to call for help right now.”  
 GO TO INTERVENE.  
 If no , “I am going to have my supervisor call you later to see how you are doing. I will also send you some resource information in the mail.”  
 Complete *Urgent/Serious* form.

SUICIDE / HOMICIDE

U **Intentionality**  
 “Have you thought about suicide/homicide? “  
 If yes, ask about a plan.  
 If no, same as above.  
 “Do you have a plan? “  
 If yes, GO TO LETHALITY.  
 If no, same as above.

U **Lethality**  
 “Do you have the means to carry out your plan?”  
 If yes, “I am going to call for help right now.”  
 GO TO INTERVENE.  
 If no, same as above.

**I n t e r v e n e**

U Establish three-way call.  
 “Please stay on the line while I call for help.”  
 U Describe situation, address, and person.  
 U Stay on the line until help arrives.  
 “Is there someone there with you now?”  
 “Promise me.....while we are waiting for help.”

**D o c u m e n t**

### Handling Urgent/Serious Situations

During the course of an interview, if the interviewer suspects that the respondent is at risk for an urgent or serious medical, physical, or psychological problem, the interviewer should follow the non-emergent assessment steps below. Urgent/serious incidents also should be reported within 24 hours to the Program Manager using the SCTBIFR Urgent/Serious Report form. See Appendix A. The project coordinator will pursue the appropriate follow-up action. Answering any of the assessment questions in the affirmative at the end of an interview will indicate that the respondent should be referred for follow-up.

#### Part I. Suicide Risk. Did you hear...?

2. Life isn't worth living
3. My family would be better off without me
4. Next time I'll take enough pills to do the job right
5. Take my [prized collection, valuables], I don't need this stuff anymore
6. I won't be around to deal with that
7. You'll/they'll be sorry when I'm gone
8. I won't be in the way much longer
9. I just can't deal with everything, life's too hard
10. Nobody understands me, nobody feels the way I do
11. There's nothing I can do to make it better
12. I'd be better off dead
13. I'm getting my affairs in order [such as paying off debts or changing a legal will]
14. I'm giving away articles of either personal or monetary value
15. I have a suicide plan [such as obtained a weapon or writing a suicide note]

#### Part II. Depression Risk. Did you hear...?

16. Depressed Mood
17. Change in sleeping patterns (too much, too little, or disturbances)
18. Change in weight or appetite
19. Speaking and/or moving with unusual speed or slowness
20. Loss of interest or pleasure in usual activities
21. Withdrawal from family and friends
22. Fatigue or loss of energy
23. Feelings of worthlessness, self-reproach, or guilt
24. Diminished ability to think or concentrate, slowed thinking or indecisiveness
25. Thoughts of death, suicide, or wishes to be dead
26. Extreme anxiety, agitation, or enraged behavior
27. Excessive drug and/or alcohol use or abuse
28. Neglect of physical health
29. Feelings of hopelessness or depression

#### Part III. Medical/Physical Risk. Did you hear reports of...?

30. Neglect of care
31. Threats of bodily harm
32. Past abuse
33. Lack of needed supervision
34. Out of control medical symptoms, e.g. blood pressure, fever, pain etc
35. Sexual abuse