# CIDI 2.1 TRAINING MANUAL FOR THE NATIONAL HEALTH AND NUTRITION SURVEY MODULE (NHANES)

(DECEMBER 1998)

NOTES BASED ON THE CIDI 2.1

### **SECTION 1: INTRODUCTION**

This manual provides instructions to the interviewer in the use of the NHANES version of the WHO-CIDI 2.1 questionnaire. Section 1 briefly describes the WHO-CIDI, and outlines general instructions for the interviewer. Section 2 provides instructions for navigating through the CAPI questionnaire, and describes conventions for different question types, and Section 3 provides general instructions to interviewers. This questionnaire has several sets of questions that are repeated throughout the questionnaire, that are explained separately in Sections 4-6 (Probe Flow, Onset/Recency, and Work Loss/Effort series). Sections 7-9 provide question by question instructions for the other questions in the questionnaire.

The Composite International Diagnostic Interview (CIDI) is a standardized questionnaire designed by the World Health Organization that is used to assess mental disorders and provide diagnoses. This version of the CIDI assesses three disorders (Panic Disorder, Major Depression, and Generalized Anxiety Disorder), in the three sections of the questionnaire.

The time needed to administer these sections will vary greatly, depending on the number and severity of symptoms the respondent reports. While most respondents will report very few symptoms and will skip out of most of the questions (with an average interview length of 5 minutes), a few respondents may take 45 minutes or longer to complete this portion of the interview.

Many of these questions are of a sensitive nature, asking about difficult times in the respondent's life. The interviewer needs to remain professional and non-judgmental throughout the interaction with the respondent. These types of questions have been asked of thousands of respondents in all walks of life, and most people (even those who have experienced problems in their life) find the interview to be an enjoyable experience. Often respondents with problems find it helpful to have someone to listen to their "story" in a non-threatening and non-judgmental manner. Using good basic interviewing techniques (asking the questions exactly as worded, using non-directive probes and feedback to encourage the respondent) to train the respondent in (his/her) role, and to maintain control of the interview will make this interview a positive experience for both the interviewer and respondent. By using good interviewing techniques the interviewer will also collect the most accurate and unbiased data possible for these (and all) sections of the interview.

# SECTION 2: WORKING WITH THE ISHELL CAI SYSTEM

### A. General Information

This program is intended to be used without a mouse.

### B. Asking Questions and Recording Answers

**Screen Layout:** The top half of the screen contains the question text and instructions to the interviewer. The bottom half of the screen contains the answer options. To record an answer, type the number that corresponds to the answer given by the respondent. As the answer is entered, the corresponding radio button will be highlighted and the answer option will change color from black to blue. Pressing ENTER will then move interview on to the next question.

All black text on the screen is read aloud to the respondent. Interviewer instructions are in blue text, and are not read to the respondent. Black letters in parentheses are optional, to be read at discretion of interviewer. All underlined words are to be emphasized when reading the text.

- **Changing answers:** To change an answer on the current screen, simply type the number corresponding to the new answer and press <Enter>.
- **String field:** This question type requires the interviewer to input an answer in an empty box, rather than choosing a single numeric option. If the information being requested is numeric (e.g. number of days), the program will only accept numeric input.
- **Time question:** This question type requires the interviewer to input both the number of (days/weeks/months/years) as well as input the appropriate unit of time. To highlight the radio button corresponding to a specific unit of time, type the first letter of the time unit. E.g. press "d" to select days, "w" to select weeks.
- **Multiple Answer questions:** This question type lists several options and allows the interviewer to record multiple answers. Use the <up> and <down> arrows to maneuver through the list and press the <space bar> to select each appropriate answer. Pressing the <space bar> a second time will deselect any previously selected answer.
- **Don't Know and Refusals:** Each question contains options for DK and REF. If these options are not listed with numeric codes, information on how to enter them is given in an interviewer instruction for that question. A text box (see below) will appear after each Refusal to allow the interviewer to record any information related to the refusal.
- **Empty:** No questions are allowed to remain empty. An answer must be provided for each question before the program will move on to the next question.
- **Remarks:** A remark can be made at any question by typing CTRL N. This will bring up a text box (Notepad) in which the interviewer can make any relevant comments.

- **Text Boxes:** The text box is the active window when it appears on the screen. Simply type any remarks directly in the box. To choose the button options OK, CLEAR, CANCEL, use the TAB key to highlight the appropriate box and press <Enter>.

# C. Navigation Keys

- **Enter> key.** Pressing <Enter> after entering a datum will cause the next appropriate question for the interviewer to appear.
- **CTRL** <- This backs the interview up to the previous question.
- **CTRL** -> This moves the interview forward one question. (Will only move forward through completed questions.)
- < Home> key: The < home> key moves the cursor to the beginning of a string entered in the text box or a string field.
- **<End> key:** The <end> key moves the cursor to the end of a string entered in the text box or a string field.

### **SECTION 3: GENERAL INTERVIEWER INSTRUCTIONS**

Below are some general instructions for interviewers to use while administering the CIDI sections.

- 1. Asking the questions
  - Ask all questions as written
  - Read complicated and long questions slowly.
  - Where necessary, repeat the question with emphasis on the frame of reference to help the respondent understand the question.

# 2. Probing rules

- If the respondent says (he/she) does not know, ask for a "best estimate."
- If the respondent's answer is a wide range (e.g., a range of more than 5 days), probe "Which is closer?" to try to get a more precise answer.
- If the respondent gives a small range, code the midpoint.
- If there is no midpoint, code the <u>lower</u> number closest to the midpoint.
- If the respondent does not know the answer even after a "best estimate" probe, code DK.

### 3. General definitions

- A few: 3 or more
- A couple: 2
- Frequently: "Whatever you think of as frequently." or "Whatever frequently means to you."
- Often: "Whatever you think of as often", or "Whatever often means to you".
- A lot: "Whatever you think of as a lot", or "Whatever a lot means to you".
- In the past month: in the previous four weeks
- 4. Use feedback to train the respondent in (his/her) role
  - Thank the respondent for giving thoughtful, precise answers.
  - Use task-related feedback (e.g., "Let me write this down") to fill in pauses while the interviewer records open ended answers or comments, or works through check points.

# **SECTION 4: PROBE FLOW QUESTIONS**

### A. Introduction

The Probe Flow questions are a series of questions that ask about a symptom, problem, or experience that the respondent has had. They are designed to determine if the symptom (or problem or experience) is "clinically significant," and if it is, to determine the cause of the symptom. Throughout the questions, the abbreviation (SX) is used to denote the symptom, problem, or experience the series is asking about. The end result of this series of questions is a variable with five response options, listed below. In CAPI, the computer automatically takes the interviewer through the sequence and assigns the proper end code. But because there are a lot of "what if" scenarios that can come up when administering these questions, it is helpful to understand what the questions are designed to measure. The categories for the variable generated by the Probe Flow questions are:

## **Code Description**

- 1. **No Problem** (The respondent did not have (SX) the symptom, problem or experience)
- **2. Not Clinically Significant** (The respondent had (SX) but it was not clinically significant i.e., not bad enough to cause problems in the respondent's life)
- 3. Medication, Drugs, or Alcohol was always the cause of (SX)
- **4. Physical Illness or Injury was always the cause of (SX)** (or the cause was always either medication, drugs or alcohol; or physical illness or injury)
- **Possible or Definite Psychiatric Symptom:** There was at least one occurrence of (SX) that is not explained by medication, drugs or alcohol; or by physical illness or injury; and the symptom may be due to a psychiatric problem. Alternatively, the respondent or medical professional may have diagnosed the respondent with a psychiatric condition.

Note that a "Probe 5" (Possible or definite psychiatric symptom) does <u>not</u> necessarily mean that the respondent has any type of mental illness. It only means that there is an unexplained instance of a symptom that <u>may</u> be caused by a psychiatric problem. All of us experience unexplained problems at one time or another; it is only people who have <u>specific patterns</u> of possible psychiatric symptoms that may be diagnosed with the conditions we are asking about in this interview.

The phrase "clinically significant" is one that also has a specific meaning for this set of questions. For this questionnaire, clinical significance is determined by asking three questions designed to find out if the (SX) is severe enough to try to identify its cause. If the (SX) did not interfere with the respondents' activities a lot; if the respondent did not seek medical help for the condition; and if the respondent did not take medication more than once for the (SX); the symptom is deemed "not clinically significant," and we do not need to determine its cause.

The attached Probe Flow Chart shows the order in which the questions will appear on the computer screen. Because the computer will automatically route the interviewer to the correct question, the instructions in this manual will focus on the meaning of the questions and the various "what if" scenarios that may come up as respondents share their real-life experiences with the interviewer.

# **B.** Question by Question Instructions for Probe Flow Questions

### "Ask Question"

The question is read to the respondent just as it is written on the screen. If it appears that the respondent has not understood the intent of the question, it should be read again, emphasizing those words which the interviewer thinks were misunderstood. The interviewer should not express dissatisfaction or disbelief at what the respondent has reported. However, if the response <u>contradicts</u> a previous response, the respondent should be asked to clarify the discrepancy.

### "Did you tell a doctor about (SX)?"

This is the first probe. When reading this probe for the first time to the respondent, the word "doctor" should be explained, using the definition given in parentheses. (Doctor includes psychiatrists, other medical doctors, and osteopaths.) If the respondent answers "no" to this question, the interviewer is directed to the question "Did you tell any other professional about (SX)?"

The answer is coded "yes" if the respondent <u>intentionally</u> sought medical advice for this symptom. This can be done in a variety of ways, including:

- The respondent made a special trip to the doctor for this symptom
- The respondent brought up the symptom while seeing the doctor for another problem
- The respondent asked about the symptom during a telephone call to the doctor
- The doctor advised the respondent that (s)he had this problem
- Someone else told the doctor about the problem
- If someone else told the doctor about a symptom (SX) the respondent had, this is equivalent to the respondent telling the doctor. For instance, as a child, the parent might have told the doctor, or as an adult, the respondent's spouse might have brought it to the doctor's attention
- The respondent told a friend or relative who is a doctor, if the intent was to seek professional advice

### >What if the respondent told the doctor only because the doctor asked?

If the respondent <u>volunteers</u> that the symptom is not a problem for him and he only told the doctor because the doctor asked as a part of a routine checkup, this does not count as having told the doctor.

### >What if the respondent isn't sure (s)he told the doctor?

A vague recollection of "I might have told my doctor" is not certain enough to count as telling the doctor. The interviewer should probe for a definite answer, such as "Do you recall a time when you told the doctor?" If respondent does not recall, code "no."

If the respondent volunteers that the professional told was not a medical doctor (does not fit the definition of doctor on the screen), the answer is treated as a "no" response to "Did you tell a doctor about (SX)," but as a "yes" response to "Did you tell any other professional about (SX)?"

# **Box A: Severity/Clinical Significance**

These questions determine if the symptom is severe enough to be considered clinically significant.

### "Did you tell any other professional about (SX)?"

When reading this probe for the first time, "other professional" must be defined to the respondent using the definition in parentheses on the screen. (Other professional includes psychologists, social workers, counselors, nurses, clergy, dentists, chiropractors, healers and podiatrists.) Telling a friend or relative who is a professional counts, if the intent was to seek professional advice. (See the instruction to the question "Did you tell a doctor about (SX)" on page 6.)

# "Did you take medication more than once for (SX)?"

Medication includes prescribed or over-the-counter (non-prescription) medicines. A prescription originally intended for someone other than the respondent counts, so long as the respondent took it to the <u>treat</u> the symptom. Taking the medication more than once counts, even if the medication does not help the problem for which it was taken.

# "Did (SX) interfere with your life or activities a lot?""

An answer such as "It interfered somewhat with my life" should not be accepted as a positive response. The question should be repeated to determine whether the respondent felt that the symptom interfered with his/her life or activities "a lot". The respondent may ask the interviewer what "a lot" of interference with life or activities means. The definition of "a lot" must be determined by the respondent, e.g. "Whatever 'a lot' means to you."

If all three "clinical significance" questions in Box A are answered "no," the probe flow section will end and interviewer will return to the main flow of the interview.

### **Box B: Physical Illness Or Injury**

This question determines whether the symptom was ever caused by a physical illness, injury, or condition.

### "Was (SX) ever the result of a physical illness of injury?"

If a (SX) happened several times and only once resulted from a physical illness or injury, the answer is still "yes."

If the response is "yes", the interviewer will be prompted to ask what the illness or injury was.

The phrase "physical illness or injury" includes incidents which may be described as "insults to the body," such as excessive exposure to the sun, noxious fumes that caused headaches, muscle soreness due to unusual physical activity, or losing one's voice after an unusually prolonged period of shouting. While pregnancy is not a physical illness, it is a physical condition that can cause symptoms and is considered an "insult to the body" for the purposes of this interview. Hyperventilation is <u>not</u> a physical illness. "Migraine" or "growing pains" do not count as physical illnesses unless a physician made the diagnosis.

Reactions to physical treatments, such as physical therapy, electroconvulsive therapy (ECT), and

radiation therapy are counted as physical injury, as long as the symptom was <u>caused</u> by the treatment. For instance, memory loss may be attributed to electroshock therapy.

If the interviewer doubts that the illness the respondent mentions could cause the symptom, the illness should be recorded and a message in the note pad should be typed in for the editor.

# "Was (SX) always the result of a physical illness or injury?"

In the flow chart, this question is located in Box D next to the large triangle. There are several paths leading to this question. If the response is "yes, the program will skip out of the Probe Flow series of questions.

"Always" means every single time. If just one time the symptom (SX) was not a result of a physical illness or injury, the answer is "no".

# "When (SX) was not due to a physical illness or injury, was it always the result of taking medication, drugs, or alcohol?"

Read this question slowly, emphasizing the words "not" and "always." If the response is "no" the program skips out of Probe Flow series of questions. If the respondent answers "yes," the interviewer will be prompted to ask what caused (SX).

### "What caused (SX)?"

This question is also asked in several places. The interviewer should record the response in the text box.

### **Box C: Medication, Drugs Or Alcohol**

These questions determine whether the symptom was ever caused by using medication, drugs, or alcohol. If (SX) was <u>ever</u> caused by any of these substances, it can then be determined whether the symptom was always caused by any of these substances.

### "Was (SX) ever the result of taking medication, drugs, or alcohol?"

This question is asking whether medicines, drugs or alcohol <u>caused</u> the symptom. Respondents may mistakenly interpret this question as asking whether medication was taken at the time the symptom occurred, or whether medicine was taken because of the symptom. Note the following:

- Anesthetics given during an operation count.
- Symptoms of withdrawal from drugs qualify as well as the direct action of the drug itself.
- Allergies to foods are considered medical illnesses, and not a drug reaction, even though they are caused by a substance.

# "Was (SX) always the result of taking medication, drugs, or alcohol?"

The same rules apply here as for the similar question in probe section of physical illness and injury. "Always" means <u>every time</u>. A "no" response skips out of probe flow section. If "yes" then the final probe question is asked:

# What kind of medication, drugs, or alcohol caused (SX)?

This question asks the interviewer to record the name of the medication, drug, or alcohol that caused the symptom. Once recorded, the respondent skips out of the probe flow sequence. (See Recording Physical, Substance-related, and Psychiatric Explanations on page 11).

### **Box D: Doctor Probes**

If the respondent told a doctor about (SX), the following questions determine from the doctor's diagnosis whether symptom is caused by:

- physical illness or injury;
- medications, drugs or alcohol; or
- a possible or definite psychiatric, emotional, or psychological problem.

# "When you told the doctor, what was the diagnosis?"

The question is asking for the <u>doctor's</u> evaluation of the cause of the symptom, not the respondent's own opinion. If the respondent says, "I told him it was ...," that is not the doctor's diagnosis. The interviewer should determine what the <u>doctor</u> said. The interviewer should use the bracketed phrase "What did the <u>doctor</u> say was causing the (SX)?" if there is any doubt as to what the doctor's diagnosis was.

There are four coding options for this question:

- Medication, drugs or alcohol: the definition of these causes are the same as listed above in the
  discussion of Box C on page 8 (remember that the medication, drug, or alcohol must <u>cause</u>
  the symptom to be counted here)
- Physical illness or injury: defined as "insult to the body" and includes such things as radiation treatment, physical therapy, laryngitis from shouting, etc. (See the Box B instructions on Page 7)
- No definite diagnosis: use this when it is not clear what the doctor's diagnosis was (either because the respondent says he/she does not know, or because the interviewer cannot determine what the doctor said and what the respondent believes to be the cause)
- Nerves, stress, anxiety, depression, mental illness: this is a "priority code" if any mention is made of a possible psychiatric symptom, choose this code. (See the list below for responses that are to be coded in this category.)
  - adjustment problems
  - anorexia nervosa
  - anxiety
  - bipolar disease
  - bulimia
  - dementia
  - depression
  - emotional problems
  - exhaustion
  - hyperventilation

- hypochondriasis
- hysteria
- mania
- manic-depression
- marital problems
- mental breakdown
- nerves
- neurosis
- overwork

- panic attacks
- personality problems
- phobia
- schizophrenia
- senility
- sexual abuse
- stress
- tension
- an upsetting event

# >What constitutes "No definite diagnosis?"

Any vague statement by the doctor suggesting possible physical illness or injury as an explanation (e.g. "Stomach trouble," "a chest problem," "hyperventilation," "exhaustion," "He thought it might be a side effect of my medication," or "He thought it could have been a result of my auto accident") should be coded "no definite diagnosis." The follow up question asking if the doctor found anything abnormal when he/she took tests or x-rays will enable the interviewer to determine whether the doctor was just speculating. If the doctor was just speculating, type a message in the notepad function of the program.

A diagnosis which is not definitive can come up in two ways. Either the doctor said the diagnosis was uncertain, or implied it was uncertain by giving several diagnoses without seeming to choose one. (e.g., "He said it could be due to my medication or it could be due to a bladder infection.") In such cases, the interviewer should code "no definite diagnosis."

# >Describing the treatment is not equivalent to a diagnosis.

If the respondent says, "The doctor gave me some pills for that problem," or "I was told to get more rest," (s)he is reporting what the doctor said to do about the problem, rather than the diagnosis. The interviewer should then ask the alternative probe, "What did the doctor say was causing (SX)?"

# >What if the interviewer is unsure about a particular diagnosis?

Sometimes the respondent might report a doctor's diagnosis and it is not clear whether it is really a physical illness or a "No definite diagnosis." In such instances the interviewer should code "No definite diagnosis." The following question that will appear if this is chosen, is: "Did the doctor find anything abnormal when he examined you or took tests or X-rays?" Thus, if anything abnormal was found, the interviewer will end up with the same sequence of questions as for the probe for physical illness.

# >What if the response to the probe about abnormal test findings is simply a mention of the tests performed?

This is a case where a response is not an answer. If the response to the question "Did the doctor find anything abnormal when he examined you or took tests or x-rays?" is, "He drew a tube of blood for the tests," this is not evidence that there were positive findings. Something abnormal must have been found during the examination to count tests as evidence for a physical illness. Repeat the question, emphasizing abnormal. If the respondent does not know what was found, code "no."

### >Do all abnormal test findings count?

When asking the question about abnormalities on tests, the interviewer is looking for results suggesting a physical basis for the symptom being probed, not simply any abnormal finding. For instance, a routine urinalysis may lead to discovery of diabetes, even though the symptoms that prompted doing the test had nothing to do with diabetes. The interviewer can clarify the relation of the abnormal findings to the symptom by adding a phrase to the probe question "Did the doctor find anything that he said explained (SX) when he examined you or took tests or x-rays?"

# >What if there is more than one diagnosis by a doctor or several doctors?

If the respondent consulted doctors for several occurrences of the same symptom, or saw more than one doctor for a single episode, multiple diagnoses may have been made. The interviewer should ask "What were their diagnoses?" If any one was a psychiatric diagnosis, code "mental illness" and note the diagnosis in the text box. The program will then skip out of the probe flow series.

If there was no psychiatric diagnosis, but the symptoms were attributed both to physical illness and ingestion of substances, the program will default to "What kind of medication, drug, alcohol caused (SX)?" If the multiple diagnoses include one or more indefinite diagnoses (but no psychiatric diagnosis), the interviewer should code "no definite diagnosis" and ask about the time when the doctor did not know the cause, even if there were clear physical explanations at other times.

# >What if there are doubts the doctor made the diagnosis that the respondent claims?

The respondent may report a diagnosis by a doctor that sounds highly improbable to the interviewer. The interviewer must accept and code according to the respondent's word. A note may be entered in the notepad function to indicate a need for review of the coding decision by the editor or a physician.

# C. Other points to remember

- 1. Several of the probes ask "Was it always..." This means every single time the symptom occurred. If the respondent's answer is "Yes, it usually was," the interviewer should probe to find out whether the respondent means "always" or "usually": "Does that mean that sometimes (SX) was not the result of taking medication, drugs, or alcohol?"
- 2. When determining what caused a symptom, the interviewer is to code only the "proximal" cause. This is defined as the condition that most <u>directly causes</u> the symptom. For example, if stress causes an ulcer, and the ulcer causes stomach pain; the proximal cause of the stomach pain is the ulcer and not stress. In this example, the "priority coding" of "stress" as a possible psychiatric diagnosis would not apply, since the stress was not the proximal or direct cause of the (SX).
- 3. If the respondent says "I don't know" to a question asking whether or not a symptom was ever experienced, enter DK and no further probing is necessary.

### D. Recording Physical, Substance-Related and Psychiatric Explanations

If a physician or osteopath gives a physical diagnosis to explain the symptom, click on the box that reads "Physical illness" or "Physical injury". A follow up open-ended question will allow the interviewer to record the physical diagnosis.

Similarly if the only occurrences of the symptom were said by a doctor to be explained by medication, drugs, or alcohol, an open-ended question will allow the interviewer to record the medication or drugs or alcohol that caused the symptom.

If a physical, substance-related, or psychiatric (or emotional or psychological) diagnosis was furnished by a professional other than a doctor <u>or</u> is the respondent's own opinion, record it in the textbox using the notepad function. It is important to note who gave the diagnosis.

# **SECTION 5: ONSET/RECENCY QUESTIONS**

For some groups of symptoms, we ask when the respondent first experienced the symptom, and when the respondent last (most recently) experienced it. The question asking about the first experience is called the "onset" question; and the question asking about the last time the respondent had the symptom is called the "recency" question.

The time frames of the response options for the onset and recency questions are listed below. Note that the time frames are mutually exclusive. For example, if at D54d.1 the respondent reports having avoided certain situations continuously for the past eight months, "in the past month" would be the correct answer to code.

- In the past month
- Past six months
- More than six months ago

## **Coding onset and recency responses:**

The guiding principles used for coding onset and recency questions are as follows:

- 1. We want to get the most accurate information. If the respondent does not know, probe by asking for the respondent's "best estimate".
- 2. If the respondent gives a large range (e.g., "in my 20's" or "sometime after I turned 40"), ask the respondent to narrow down the range by probing "Which is closer?"
- 3. If the respondent gives a small range (e.g., "15-17") code the midpoint of the range (in this example, the midpoint would be 16)
- 4. If the respondent gives a range with no midpoint, choose the number that is closest to the midpoint and will give the biggest time period of experiencing the symptom.
  - For recency, round <u>up</u> (code the older age) (For example, a response of "25 or 26" would be coded "26")
  - For onset, round <u>down</u> (code the younger age) (For example, a response of "30 or 31" would be coded "30")

# SECTION 6: WORK LOSS/EFFORT QUESTIONS

### A. Introduction

This set of questions assesses the degree to which a symptom has "interfered" with the respondent's life. They appear in several places throughout the questionnaire. Many of the questions in this section are long and very complex, and it is important for the interviewer to read the questions slowly. It may also be necessary to repeat these questions stressing the frame of reference if the respondent thinks (he/she) has already answered them, and pause to give the respondent time to think about the answer.

The general pattern of these questions is the same throughout this series:

- 1. Ask about the number of days (SX) has had a specific impact on the respondent
- 2. If any, ask how many days in the past four weeks this occurred

# B. Probing and recording rules

Because this interview contains many questions that ask for the precise duration of specific symptoms, respondents who have had many of the symptoms in the questionnaire may need encouragement to think carefully and to work hard to provide accurate information. Feedback (neutral phrases such as "thanks, this is helpful information") should be used to help encourage the respondent to give accurate answers. Neutral probes may also be needed to help guide the respondent to an answer that meets the question objectives.

There may be times where the respondent's answers seem contradictory. (For example, a respondent may report having had a particular symptom for 365 days out of the past year, but then say (she/he) did not have it at all in the past month.) In these cases, use your best judgement about probing. If the respondent obviously has misunderstood the question or missed the frame of reference (either the time period or the symptom to which the question is referring), repeat the question and try to clarify the discrepancy. If, on the other hand, the respondent appears to understand the questions and there is a small discrepancy (e.g., the sum of the days reported in the "4 weeks" questions adds up to 30 days instead of 28), do not probe.

See also Section 3 for general probing rules to be used for these questions.

### **Recording rules:**

- If the respondent answers in terms of weeks, multiply the number of weeks by 7 and record the number of days.
- If the respondent answers in terms of months, multiply the number of months by 30 and record the number of days.

### C. Question-by-question objectives

### **Unable to Work**

About how many days in the past 12 months were you <u>totally unable</u> for the whole day to work and carry out your other normal activities because of (SX)? You can answer with any number between 0 and 365.

The first question of this series asks about days the respondent was <u>totally unable</u> to work for an entire day <u>because</u> of the symptom. This question can be difficult for respondents to answer, because they need to calculate the number of days this happened over an entire year. Pause briefly to encourage the respondent to think about the answer, and probe using the general guidelines as necessary. When reading the question, emphasize the phrase totally unable.

If the respondent volunteers that (he/she) does not work for pay, repeat the question emphasizing the phrase carry out your other normal activities.

### **Cut Back Days**

(Not counting the days you were totally unable to work,) about how many (other) days in the past 12 months did you <u>cut back</u> either on the <u>amount</u> of work you got done or on the <u>quality</u> of your work because of these problems? (Again, you can use any number between 0 and 365.)

This question asks the respondent to think about days when (he/she) was impaired due to (SX), but still could get some work done and could carry out some of (his/her) daily activities. If necessary, repeat the question, emphasizing the phrase not counting the days you were totally unable to work. (This introductory phrase will only appear if the respondent gave a number other than "0" in response to the "unable to work" question above.)

If the respondent replies that (he/she) does not work for pay, tell the respondent that "work" in this question refers to carrying out normal daily activities (which includes all things usually done in a day).

### **Rate Quantity and Quality of Work**

Thinking about those (X) cutback days, on a scale from 0 to 100 where 0 means being totally unable to work and 100 means working a full high-quality day, what number describes the quantity and quality of your work during those (X) days? You can use any number between 0 and 100.

The "(X) cutback days" in this question refers to the number of days reported in the "cutback" question above. The respondent is asked to rate (his/her) own performance on a scale of 1-100 for days during which (he/she) was working at reduced capacity because of (SX). This is a complex question, and should be read slowly.

If the respondent says "it varied" or indicates that some days were better than others, ask the respondent to provide you with an <u>average</u> score for all the "cutback" days combined.

### **Extreme Effort Days**

(Not counting the days you were totally unable to work and the days you cut back on work), about how many (other) days in the past 12 months did it take an extreme effort to perform up to your usual level at work or at your other normal daily activities because of (SX)? (Again, you can use any number between 0 and 365)

This is another complicated question, in which the interviewer is asking the respondent to:

- think of the entire past year,
- identify all the days that (he/she) was <u>totally unable to work</u> or was at <u>reduced capacity due</u> to (SX); and
- report how many days (of the remainder) that (SX) <u>caused</u> (him/her) to have to <u>exert great</u> effort to perform up to normal standards.

To help the respondent work through this question, read it slowly and pause at the end to give the respondent time to think. If the respondent replies "all the other days of the year," or "all the time," calculate the remainder (i.e., 365 – days unable to work – cut back days).

This question refers to days where extreme (i.e., very unusual) effort is needed because (SX) was making it difficult to perform. For some respondents, that may really be every day. But we do <u>not</u> want respondents to answer "every day" if they simply think of themselves as hard working people. If you think the respondent misunderstood the question, repeat it slowly emphasizing the phrase <u>extreme effort</u>.

Note that the sum of the three questions asking for number of days (unable to work, cutback days, and extreme effort days) should not add up to more than 365 days. At this point in the interview, the interviewer may notice that there is a large discrepancy (e.g., R reported being unable to work for 2 weeks and had a month of reduced ability, and then answers "365" for the "extreme effort" question). If that happens, probe by repeating the question, emphasizing the phrase not counting days you were totally unable to work or had to cut back on the amount or quality of your work.

### Personal/Social Life

And about how many days in the past 12 months did (SX) seriously interfere with your personal or social life? You can answer with any number between 0 and 365.

This question changes the frame of reference from "work" and "normal daily activities" to "personal or social life." If the respondent asks what is meant by "personal or social life," the interviewer should respond with "Whatever it means to you." The number of days that (SX) interfered with the respondent's personal or social life may be the same, or may be different from the answers reported above for "work" and "normal daily activities." When reading this question, stress the phrase personal or social life to help distinguish it from the previous questions.

# Section 7: Panic Disorder Question-by-Question Objectives

### A. Introduction

The essential feature of Panic Disorder is a panic (anxiety) attack that occurs suddenly and unpredictably, though certain situations, e.g., driving a car, may become associated with a panic attack. The same symptoms occurring during marked physical exertion or in a life threatening situation is not termed a panic attack.

A panic attack is manifested by a <u>sudden</u> onset of intense apprehension, fear, or terror, often associated with feelings of impending doom. The most common symptoms experienced during an attack are: shortness of breath; heart pounding; chest pain or discomfort; choking or smothering sensations; nausea or abdominal distress; dizziness; feelings of unreality; tingling in the hands or feet; hot flushes or chills; sweating; faintness; trembling or shaking; dry mouth; and fear of dying, going crazy, or doing something uncontrollable during the attack. Attacks usually last minutes, rarely hours.

Panic attacks are classified into those which occur only in the presence of the object of a phobia and those which occur at other times.

If the respondent indicates that (he/she) has had only one attack in the past 12 months and it was due to a life-threatening situation, the respondent meets inclusion criteria and is taken through most of this section. The respondent then may (depending on the response pattern) be taken through the work loss and cutback day questions which will ask about the one incident. This may seem redundant to the respondent, but the interviewer should tell the respondent that each question needs to be asked in the order in which it appears in the questionnaire.

# **B.** Question-by-Question Specifications

- D54 The interviewer should emphasize the words, <u>sudden</u> and <u>felt frightened</u>, <u>anxious or very uneasy</u>.
- D54.1 This is a "second chance" question, which asks about panic attacks in a slightly different way. The purpose of this question is to make certain that no one is skipped out of this section in error.
  - The phrase "out of the blue" means "for no apparent reason"
- D54b This question refers to the respondent's <u>concern</u> about having another attack, whether or not an attack actually occurred.
- D54c.1 The "ongoing concern" in this question refers to the concern mentioned in D54c, "that the attacks might lead to something terrible happening."
- D55 This question ascertains whether any of the panic attacks someone has had occurred in a life-threatening situation. The definition of "life-threatening" is whatever the respondent thought was life threatening at the time of the incident.

D57 This question refers only to symptoms that occurred during the most recent panic attack that was not in a life-threatening situation.

Card A is handed to the respondent at the beginning of this question. The interviewer should read each item to the respondent, even if the respondent volunteers that (he/she) has had some of the symptoms on the card. For items that have more than one option (e.g., ""hot flushes" or "chills"), a "yes" to either option counts as a "yes" for that item.

D59 Note that this question refers to the number of panic attacks the respondent has had in his/her entire lifetime. To qualify, the attacks must be accompanied by some of the symptoms listed in D57.

This can be a difficult question for respondents, especially if they have had many panic attacks over a long period of time. If necessary, probe "What's your best estimate?" to encourage the respondent to come up with a number. Code "900" for 900 or more attacks. In the follow-up questions that refer to these attacks, the text will show up as "900" on the computer screen, and the interviewer can modify the question to read "900 or more" where appropriate.

- D59.2c This question is very lengthy and complex. Read slowly, and repeat the key phrases and/or read the last phrase in parentheses if the respondent has not understood the entire meaning of the question.
- D59.2d If the respondent has had a panic attack in a situation where the respondent had an unusually strong fear, this question asks what that fear is. Probe to determine in which situation the panic attack occurred if not volunteered by respondent.

If the respondent mentions a fear of something not on the list, code "other" and record the fear in the text box.

- D60 Emphasize the words exact and very first when reading this question.
- D60c This question is very similar to D60. There is a subtle difference (D60 asks the respondent to recall (his/her) exact age at (his/her) first panic attack; and D60C asks the respondent to recall the earliest age (he/she) can clearly remember an attack). It is possible that the respondent knows (he/she) had panic attacks at a very young age, but does not remember them clearly.
- D59a This is a complicated question. Read slowly. The respondent is asked to divide the total number of panic attacks in (his/her) lifetime into those that occur "out of the blue" (for no particular reason), in situations of unreasonably strong fear, and in situations of real danger.

There is no check to be sure that the sum of the panic attacks in these three situations adds up to the total number of panic attacks reported by the respondent. If the respondent has obviously misunderstood the question, probe to get an accurate number; but do not attempt to force the numbers to add up to the total number of attacks.

D59d If the respondent has had panic attacks in situations where the respondent had an unusually strong fear, this question asks what those fears are. Probe to determine in which situation(s) the panic attacks occurred if not volunteered by respondent. Probe "any others?" until the respondent answers "no," and check all that apply.

If the respondent mentions a fear of something not on the list, code "other" and record the fear in the text box.

- D59.5d Code "900" for 900 or more attacks.
- D59.5e A "four-week period" in this question refers to four consecutive weeks. Code "900" for 900 or more attacks.
- D59.5f Read this question slowly. To code "yes," the respondent must have had four or more attacks every week for four consecutive weeks.
- D58a This question begins the Probe Flow series of questions.
- D62 This is a long and complicated question. Read slowly. The question asks the respondent to indicate how much the panic attacks have interfered with (his/her) life in any way. If the respondent replies that some attacks interfere a lot and others do not, probe "In general, how much did these things interfere with your life or activities in the past 12 months?"

"Incapacitating" is defined as "making someone unable to do anything."

- D62a The "problems" that this question refers to are those listed in the previous question:
  - the incapacitating effect of the attacks themselves,
  - worry about the attacks getting in the way of daily activities, or
  - avoiding certain situations (for fear of having additional attacks) that interferes with daily activities.

The respondent must be <u>totally</u> incapacitated for an <u>entire</u> day to have the day counted for this question. If the respondent reports being totally incapacitated only for a few minutes (or hours) during and after the panic attack, this day would be counted in D62b (the "cut back" question).

# SECTION 6:GENERALIZED ANXIETY DISORDER (GAD)

### A. Introduction

The essential feature of this disorder is unrealistic or excessive anxiety and worry about two or more life circumstances for six months or more, during which the person has these concerns more days than not. Accompanying the anxiety are many signs of motor tension, autonomic hyperactivity, and vigilance and scanning.

# **B.** Question-by-Question Specifications

- D63 It is important to read this question slowly and carefully.
- D64d This question asks the respondent to indicate the types of things that (he/she) worried about. The interviewer is instructed to probe "Anything else?" until the respondent answers "No."
- D64d.1 This item is the first of a series of questions to be coded by the interviewer based on the respondent's answer to D64d. The answers to these checkpoints will determine the skip patterns for the remainder of the section. These questions are not read aloud to the respondent, and the interviewer may use task-related feedback such as "It will be just a moment while I code a few items on the computer," to fill the gap in the questioning.
- D65.1 Hand Card B to the respondent prior to asking this question. Each item should be read aloud to the respondent even if (he/she) volunteers an answer from the card before the item is read.
- D66 This is the start of the Probe Flow questions.
- D69c This question is very similar to D69. There is a subtle difference (D69 asks the respondent to recall (his/her) exact age at (his/her) first period of worry, tension, or anxiety; and D69C asks the respondent to recall the earliest age (he/she) can clearly remember such a period). It is possible that the respondent knows (he/she) had periods of worry, tension or anxiety at a very young age, but does not remember them clearly.

# **SECTION 7: MAJOR DEPRESSION**

### A. Introduction

A Depressive Episode consists of at least two weeks characterized by feelings of sadness or lack of interest or pleasure, along with other symptoms such as poor appetite, difficulty sleeping, feelings of worthlessness or guilt, decreased energy, and thoughts of death.

### **Synonyms for Depression**

There are three different questions that are used to measure depression, because people use many different terms to describe the condition. E1 asks about low mood and other synonyms for depression, namely "sad or depressed or empty." For respondents that say "no" to E1, a "second chance" question is asked (E2), where we ask about "loss of interest." And for respondents that say "no" to E2, we ask a "third chance" question (E2.1) that asks about being "irritable, grouchy, or in a bad mood."

## Assessing symptoms within a Depressive Episode

The symptoms described in E2.1c.1 to E18 must occur during a period of two weeks or longer of feeling depressed, having lost interest in most things, or being irritable or grouchy. They must be present almost every day for at least two weeks. If the respondent's answer suggests the event might have lasted less than two weeks ("Sometimes I do have that problem"), the interviewer should ask "Did that last for a period of two weeks or more?" The symptom must last most of the two week period, but interruptions of one or two days would not negate it if the total time was two weeks or more. Questions asking about thoughts of suicide and suicide attempts have no duration requirements; any occurrence is considered significant.

# **Change in Status**

The symptom questions (E2.1c.1 to E18) in depression refer to a change in the respondent's status. If a person always has the problem and it is always of the same intensity, it does not count as a symptom of a depressive episode.

In some questions (e.g., E10, E15, E15A, E16, E17) the idea of change in status is incorporated into the question. For these, if the respondent says he was "always like that", the interviewer should repeat the question, emphasizing the phrase that indicates change in status.

# **B.** Question-by-Question Specifications

- E1 Read the question slowly. It is important to relay to the respondent that the feelings of depression, feeling sad, or empty must have occurred for a period of at least two weeks.
- E1c Read this question slowly and hand Card C to the respondent. It is not necessary to read Card C to the respondent, since the information on the card is also contained in the text of the question. To answer "yes" to this question, the respondent must have had at least one of the symptoms listed on Card C at the same time as the period of depression.
- E1c.1 This question asks the respondent to identify the period of depression in the past 12 months that

was accompanied by the largest number of problems (from E1c, and listed on Card C). Note that this may not be the two-week period when the respondent felt most severely depressed, or caused the greatest impairment.

If the respondent can't choose one period of depression as having the largest number of problems, the instructions are to ask the respondent to think about the most recent two-week period of depression.

- E1d This question refers to the period identified in the previous question (E1c.1).
- E2 This is a "second chance" question for this series.

Read this question slowly, and emphasize the duration of "two weeks or longer." The loss of interest does not have to be absolute, but it must be general. A response like "I quit paying attention to the news" is not sufficient.

- E2c If the respondent does not already have Card C from the E1 series of questions, hand Card C to the respondent at this time. It is not necessary to read Card C to the respondent, since the information on the card is also contained in the text of the question. To answer "yes" to this question, the respondent must have had at least one of the symptoms listed on Card C at the same time as the period of losing interest in things.
- E2c.1 This question asks the respondent to identify the period of depression in the past 12 months that was accompanied by the largest number of problems (from E2c, and listed on Card C). Note that this may not be the two-week period when the respondent felt most severely depressed, or caused the greatest impairment.

If the respondent can't choose one period of depression as having the largest number of problems, the instructions are to ask the respondent to think about the most recent two-week period of depression.

- E2.1 This is the "third chance" question for the major depression section. The E3 series of questions will be asked if the respondent answered "no" to E1 or E2, or did not meet full criteria at some point in the E1 or E2 series. The E3 series asks the same set of questions as E1 and E2, with the frame of reference "feeling irritable or grouchy or in a bad mood."
  - Read this question slowly. Emphasize "most of the time" when asking about feelings of irritability, grouchiness, or bad mood. It is not uncommon for a respondent to answer this third chance and continue with the remainder of the depression section.
- E2.1c If the respondent does not already have Card C from the E1 or E2 series of questions, hand Card C to the respondent at this time. It is not necessary to read Card C to the respondent, since the information on the card is also contained in the text of the question. To answer "yes" to this question, the respondent must have had at least one of the symptoms listed on Card C at the same time as the period of irritability.
- E2.1c.1: This question asks the respondent to identify the period of depression in the past 12 months that was accompanied by the largest number of problems (from E2.1c, and listed on Card C). Note that this may not be the two-week period when the respondent felt most severely depressed, or caused the greatest impairment.

- If the respondent can't choose one period of depression as having the largest number of problems, the instructions are to ask the respondent to think about the most recent two-week period of depression.
- E4 This question asks about having less appetite than usual during the two week period of depression with the largest number of problems listed on Card C.
- E5 This question asks about losing weight without trying to. If the respondent volunteers (he/she) was on a diet or was trying to lose weight, code "no."
- E5a A respondent may say that (he/she) did lose weight but does not know exactly how much weight was lost in that specific two-week period. The respondent may only know over the course of a year how much weight (he/she) lost. Probe with: "What is your best estimate?" If the respondent really cannot estimate an approximate number of pounds, code DK: 998 and record any additional information in the comment screen.
- E6 This question asks about having a larger appetite than is usual (change in status) during the two-week period.
- E7 If the respondent volunteers (he/she) gained weight due to pregnancy or regaining weight loss, code "no."
- E7a A respondent may say that (he/she) did gain weight but does not know exactly how much weight was gained in that specific two-week period. The respondent may only know over the course of a year how much weight (he/she) gained. Probe with: "What is your best estimate?" If the respondent really cannot estimate an approximate number of pounds, code DK: 998 and record any additional information in the comment screen.
- Note that any of three kinds of sleeping trouble qualifies in this question: trouble falling asleep, waking in the middle of the night, or waking up too early. At least one of the three has to occur for two weeks, but it does not have to be the same one every night.
- E8a Emphasize the words <u>every day</u> when reading this question. If the respondent says (he/she) woke up two hours before (he/she) wanted to on some days during the two-week period (but not every day), the answer should be coded "no."
- E9 The frame of reference for this question is "almost every day," as defined by the respondent.
- E12b The interviewer must probe "Any other reason?" until no other reasons given. Record the respondent's answer verbatim.
- E12c The symptom being assessed is feelings of worthlessness or excessive or irrational guilt. We need to know if these feelings are caused <u>only</u> by the respondent's distress over the impairment due to the episode of depression. For example, if the respondent says, "I felt worthless because I was so tired all the time that I couldn't get my work done", code "yes." However, if the respondent says, "I felt like my whole life was pointless and that I had always been a burden on my family" or "I thought I was to blame for my brother's suicide because I had been angry with him," the answer would be coded "no."
- E15 The interviewer should emphasize the phrases <u>a lot more</u> and <u>than is normal for you</u>. If the respondent often has trouble concentrating and never had two weeks when the trouble was worse

- than usual, the interviewer should code "no" because there has not been a change in status of sufficient duration.
- E22 If the respondent says that it occurred in the opposite order, (that (he/she) felt good when (he/she) woke up, but felt bad after the day went on), code "no" and note the response in the comment box.
- E23 If the respondent indicates (he/she) is not currently sexually active, repeat the question emphasizing <u>your interest</u> in sex.
- E24 If the respondent says, "I don't know, because nothing good happened during those two weeks," code "no."
- Read carefully and emphasize weeks as the measurement respondent should come up with. The respondent is asked to think of the time in the past 12 months (he/she) was depressed and had some of the problems listed. If the respondent gives the duration of a single symptom (eg., I couldn't sleep for 16 months"), (he/she) has missed the intent of the question. The question should be repeated emphasizing the other problems.
  - If the respondent answers "about two weeks," probe to make sure it is 14 days. If the answer is 14 days, code "02" and if the answer is between 7-13 days, code "01." For partial weeks, round down (e.g., 3 ½ weeks is coded "03").
- E24b Record the length of time the period of (SX) has been going on.
- E24g If more than one person died, code the first person the respondent mentions.
- E26h If more than one person died, code the first person the respondent mentions.
- E25c If more than one person died, code the first person the respondent mentions.
- E25k If more than one person died, code the first person the respondent mentions.
- E26m This is an open-ended question allowing the respondent to explain any other events that happened that could have caused depressive periods to begin. Record the respondent's answer verbatim, and probe for clarification as needed.
- E28 Start of Probe Flow section.
- E29 The onset question should be asked by the interviewer emphasizing <u>exact</u> and <u>very first</u>. The question refers to the whole episode (feeling and problems), not individual symptoms.
- E29.1 This question is asked if the respondent does not remember how old (he/she) was the very first time (he/she) had a period of this sort. The respondent is asked to estimate about how old (he/she) was the first time (he/she) had a period of depression of this sort.
- E29.2 This question is very similar to E29. There is a subtle difference (E29 asks the respondent to recall (his/her) exact age at (his/her) first period of depression; and E29.2 asks the respondent to recall the earliest age (he/she) can clearly remember such a period). It is possible that the respondent is aware of having periods of depression at a very young age, but does not remember them clearly.