

HEALTH AND LIFE PROFILE: PART B

INSTRUCTIONS: For the next series of questions, please answer Yes or No, whichever best describes you. If you cannot decide or don't know, please indicate "Don't Know".

(CIRCLE ONLY ONE LETTER)

	<u>Yes</u>	<u>No</u>	<u>Don't Know</u>
1. Do you often feel tired?	Y	N	D
2. Do you often have trouble falling asleep?	Y	N	D
3. Do you wake up repeatedly during the night?	Y	N	D
4. Do you feel weak all over?	Y	N	D
5. Do you have the feeling that you haven't been accomplishing much lately?	Y	N	D
6. Do you have the feeling that you can't cope with everyday problems as well as you used to?	Y	N	D

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A-75

(CIRCLE ONLY ONE LETTER)

	<u>Yes</u>	<u>No</u>	<u>Don't Know</u>
7. Do you believe that you have come to a "dead end"?	Y	N	D
8. Do you lately feel more listless than before?	Y	N	D
9. Do you enjoy sex as much as ever?	Y	N	D
10. Have you experienced a feeling of hopelessness recently?	Y	N	D
11. Does it take more time to grasp a difficult problem than it did a year ago?	Y	N	D
12. Do little things irritate you more lately than they used to?	Y	N	D
13. Do you feel you want to give up trying?	Y	N	D
14. Do you feel fine?	Y	N	D
15. Do you sometimes feel that your body is like a battery that is losing its power?	Y	N	D
16. Would you want to be dead at times?	Y	N	D

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(CIRCLE ONLY ONE LETTER)

	<u>Yes</u>	<u>No</u>	<u>Don't Know</u>
17. Do you have the feeling these days that you just don't have what it takes any more?	Y	N	D
18. Do you feel dejected?	Y	N	D
19. Do you feel like crying sometimes?	Y	N	D
20. Do you ever wake up with a feeling of exhaustion and fatigue?	Y	N	D
21. Do you have increasing difficulty in concentrating on a single subject for long?	Y	N	D

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For Administrative Use Only.

22. Date / / 23. Administration (A,B,C) 24. Code

INSTRUCTIONS FOR THE HEALTH AND LIFE PROFILE FORMS
HPA, VERSION A, 1/09/90
PREPARED 08/15/90

The HEALTH AND LIFE PROFILE forms (HPA, HPB, and HPC) are designed to measure quality of life, social relationships, symptoms of fatigue and anger. They are intended to be self administered, but if necessary, can be interviewer-administered (all interviewer-administered in Jackson). They are also among the few forms for which the data entry screens are different from the paper versions. The primary difference between the paper and screen versions, in addition to the obvious format differences, is the inclusion of a "don't know" response in the screen versions of HPA and HPC, to document that the participant did not complete either the question or the questionnaire.

The Health and Life Profile forms will be stapled together with a single cover sheet and administered in a private, quiet area.

The following scripts serve as prototypes and should be adapted to meet the needs of the participant and field center.

We next have some questionnaires asking how you feel about your life and health. They are intended for you to complete by yourself.

There are instructions and similar type questions on each part of the form. (SHOW THE PARTICIPANT THE FIRST PAGE OF EACH FORM.) Will you be able to do these or would you like me to complete them with you?

If the participant needs assistance, skip to Section II.

I. SELF-ADMINISTRATION

VERIFY THAT THE FORM COVER SHEET HAS THE CORRECT ID LABEL. Provide overall instructions for completing the forms and indicate where you can be found if the participant has questions.

READ THE INTRODUCTORY SCRIPT.

The Health and Life Profile has 3 parts, with a total of 60 items that will go very quickly. There are 3 questions at the end of each part that you should ignore. These are filled out by ARIC staff. Most questions ask you to circle a letter or number under or beside the answer that best describes you. (GO OVER HPA ITEM 1 AS AN EXAMPLE.) You may be required to skip a question or two depending on your answers. (GO OVER HPA ITEM 19 AS AN EXAMPLE.) There are no right or wrong answers. We are interested in your feelings and opinions.

Please take your time to answer carefully. If you have any questions, I will be (INSERT YOUR WHEREABOUTS). I will check back with you in a few minutes to see how you are doing. If at any time you feel you need my assistance, please let me know.

If the person has specific questions about the profile, provide neutral information only. Terms like "often" and "recently" are used frequently. Their definitions are left to the participant's own preference or perception.

If the participant begins and then asks for assistance in completing part or all of the forms, offer to complete the form(s) with him/her. (See the instructions in Section II).

After allowing 20 minutes for the participant to complete the forms, clinic staff should check with the participant and decide if he/she needs assistance in completing the forms.

Field centers determine at what point in the exam the 3 forms are reviewed for completeness and what procedures should be implemented to assist the participant in completing them before the Exit Interview.

COLLECT THE FORMS from the participant. VERIFY that you have all three parts.

Scan the forms for completeness. When the forms are completed but there are one or more questions left blank, offer the participant the opportunity to complete them.

I've noticed that there are one or more questions left blank. Would you like to do them or have you left them blank on purpose?

Depending on the answer, return the form to the participant and collect it after he/she has finished. Once the participant has answered all the questions he/she intends to, document the completion status of each form. This is done in two ways. (1) To document deliberately unanswered questions, write "no response" in the margin to the right of each unanswered question in forms HPA or HPC. Do not document the completion status of individual questions in form HPB. (2) To document that the participant answered NO questions on a form, write "not done" in the margin to the right of the question "Type of Administration," located in the administrative section of that form (HPA, Item 31; HPB, Item 23; HPC, Item 12). Notes on the completion status of single questions or entire forms are later keyed into the data entry system.

The "For Administrative Use Only" section of each form must be completed by the interviewer after the form has been reviewed for completeness. If the participant completed the form without assistance, then the type of "Administration" should be recorded as "A" for self-administered. If the participant started a form and interviewer assistance was provided before all the questions on that particular form were completed, then record "C" for both participant and interviewer administration.

II. INTERVIEWER ADMINISTERED

If the participant requests help with one or more of the forms, offer to administer the paper version. As some items may be perceived as sensitive or embarrassing, statements and questions need to be read in a nonjudgemental tone.

The participant's literacy status and visual acuity should have been established during Visit 1 or at the Reception Station at the beginning of Visit 2 and documented on his/her itinerary form. Staff need to be sensitive to the participant's possible reluctance to admit (functional) illiteracy or deterioration of visual acuity since the last visit.

VERIFY THAT THE FORM COVER SHEET HAS THE CORRECT ID LABEL. If FORM HPA was begun and could not be completed without assistance, the remainder can be completed together. Follow the procedures for FORM HPA (below) and COMPLETE

THE ADMINISTRATIVE SECTION OF FORM HPA BY CIRCLING RESPONSE C, FORM HPA was both self and interviewer-administered.

THE LARGE PRINT RESPONSE CARDS ARE USED TO ASSIST ALL PARTICIPANTS AND ARE USED EVEN IF HE/SHE APPEARS NOT TO BE ABLE TO READ.

(i) PROCEDURES FOR THE INTERVIEWER ADMINISTRATION OF FORM HPA.

READ THE INTRODUCTORY SCRIPT.

As I mentioned, these questions ask about how you feel about your life and health. There are no "right" or "wrong" answers. We are interested in your feelings and opinions. For example, let me show you the first response card and go through the first question.

GIVE THE PARTICIPANT RESPONSE CARD 1, which lists the valid responses for Question 1. READ THE RESPONSES "a" to "f" TO THE PARTICIPANT.

Question 1. READ THE QUESTION. Ask if the participant would like to listen to the responses again. Read the responses again if appropriate. RECORD THE RESPONSE. If the participant refuses to answer the question, write "no response" in the right hand margin.

Question 2. Ask the participant to turn HPA Card 1 over to look at the scale. READ THE RESPONSES. Explain that "0" means "Extremely satisfied" and "10" means extremely dissatisfied. "5" is average satisfaction. READ THE QUESTION. If appropriate, ask if the participant would like to listen to the responses again. RECORD THE RESPONSE on the form. If the participant refuses to answer the question, write "no response" in the right hand margin. Retrieve HPA CARD 1 from the participant after completing question 2.

Questions 3-18. READ THE DIRECTIONS to the participant.

The following statements may or may not be true about you. For each statement, give me the response that reflects your feelings.

Terms like "often" and "recently" are used frequently. Their definitions are left to the participant's own preference or perception. If the participant asks what "often" or "recently" mean, respond: "Use it the way you would normally use it in conversation."

GIVE THE PARTICIPANT HPA CARD 2 which lists the valid responses to questions 3-18.

READ THE RESPONSES "a" to "d" on the card to the participant. When the participant catches on, omit reading the repetitive responses for each question. RECORD THE RESPONSES on the form. If the participant refuses to answer a question, write "no response" in the right hand margin. Retrieve HPA CARD 2 from the participant after completing question 18.

Questions 19 to 29. READ THE DIRECTIONS to the participant.

Now I would like to ask you some questions about your social contacts. There is no response card for the next set of questions, so I will read the question and then the responses. If you need either repeated, please tell me and I will repeat it.

READ EACH QUESTION FROM THE FORM. READ THE VALID RESPONSES FOR EACH QUESTION. RECORD THE RESPONSES ON THE FORM. Note that several questions (items 19, 22 and 27) have SKIP PATTERNS. If the participant refuses to answer, record "no response" in the right hand margin.

Valid responses for the questions on the number of relatives/friends (items 19, 21, 22, and 23) are:

- a. Zero
- b. One
- c. Two
- d. Three or four
- e. Five to eight
- f. Nine or more.

Valid responses for questions on the frequency of contacts with relatives/friends (items 20 and 24) are:

- a. Less than monthly
- b. Monthly
- c. A few times a month
- d. Weekly
- e. A few times a week
- f. Daily

Valid responses for questions on the frequency of consulting with or being consulted by relatives/friends (items 25 and 26) are:

- a. Always
- b. Very often
- c. Often
- d. Sometimes
- e. Seldom
- f. Never

Valid responses for the question on the reliance of others for daily assistance (item 27) are YES and NO. Emphasize that this reliance must occur EACH DAY. If the response is NO, record and go to item 28. If YES, record and skip to item 29.

Valid responses for question 28 are: (Note the response "always" is not valid.)

- b. Very often
- c. Often
- d. Sometimes
- e. Seldom
- f. Never

Valid responses for question 29 are:

- a. Live with spouse
- b. Live with other relatives, in-laws or friends
- c. Live with other unrelated individuals (e.g., paid help, Board and Care homes, or skilled nursing facilities)
- d. Live alone

If the participant does not live alone and responds "lives with other people", ask "WHICH OF THESE STATEMENTS DESCRIBES THE RELATIONSHIP TO YOU?" and record the first response that applies. If the participant refuses to answer, record "no response" in the right hand margin.

Questions 30 to 32. COMPLETE THE ADMINISTRATIVE SECTION. (Do not read to the participant.) For Item 31, if you administered the entire form, record B for interviewer administered. If the participant started the form, but you provided assistance at some point before all the questions were answered, record C to indicate that administration was both self and interviewer-assisted. If the participant refused to answer any questions, record "no response" in the right hand margin. The "no response" code is recorded during data entry into the DES.

(ii) PROCEDURES FOR THE INTERVIEWER ADMINISTRATION OF FORM HPB.

READ THE INTRODUCTORY SCRIPT.

This questionnaire asks you to describe how you feel about your life and health. You may take your time to answer carefully. There are no "right" or "wrong" answers. We are interested in your feelings and opinions. For the following questions, please answer Yes or No, whichever describes you best. If you cannot decide or don't know, tell me "Don't Know".

GIVE HPB CARD 1 TO THE PARTICIPANT. READ THE RESPONSE CATEGORIES (Yes, No and Don't Know) before you read the first question and continue to read the responses after each question until the participant remembers the categories. They do not need to be read once he/she memorizes them.

Questions 1 to 21. READ EACH QUESTION in a nonjudgmental tone. CIRCLE THE LETTER CORRESPONDING TO THE PARTICIPANT'S RESPONSE. If the participant refuses to answer a question, record "no response" in the right hand margin and go on to the next question. RETRIEVE HPB CARD 1 after completing question 21.

Questions 22 to 24. COMPLETE THE ADMINISTRATIVE SECTION at the end of Part B. For Item 23, if you administered the entire form, record B for interviewer administered. If the participant started the form, but you provided assistance at some point before all the questions were answered, record C to indicate that administration was both self and interviewer-assisted. If the participant refused to answer any questions, record "no response" in the right hand margin. The "no response" code is recorded during data entry into the DES.

(iii) PROCEDURES FOR THE INTERVIEWER ADMINISTRATION OF FORM HPC.

READ THE INTRODUCTORY SCRIPT

This questionnaire is like the other ones you have done in that it asks you to describe how you feel about your life. There are no "right" or "wrong" responses. We are interested in your feelings and opinions. For the following statements, please choose the one response that best describes you.

GIVE HPC CARD 1 TO THE PARTICIPANT. Following the procedures for reading and repeating response categories in HPA and HPB, READ THE RESPONSE CATEGORIES (a) Almost never, (b) Sometimes (c) Often, and (d) Almost always. Then READ EACH STATEMENT and CIRCLE the letter corresponding to the response or WRITE in the margin "No response" for later keying

if the participant declines to select a response. RETRIEVE HPC CARD 1 and COMPLETE the administrative questions (items 11-13).

THANK THE PARTICIPANT AND TAKE HIM/HER TO THE NEXT WORKSTATION.

III. KEYING DATA FROM FORMS HPA, HPB, AND HPC.

The HEALTH AND LIFE PROFILE form should be keyed as soon as possible, preferably by the interviewer responsible for its completion. If the participant answered none of the questions on the form, the interviewer enters the header information and selects the response "Did Not Respond" to the question "Type of administration" in the ADMINISTRATIVE SECTION (HPA: item 31; HPB: item 23; and HPC: item 12). This is done in lieu of completing the "Did Not Respond" response for every field.

IV. SCORING OF THE HEALTH AND LIFE PROFILE QUESTIONNAIRE

The scores for each component of the Health and Life Profile will be calculated after the data have been sent to the Coordinating Center.

V. PARTICIPANT SAFETY

The interviewer observes the participant during and immediately after the completion of the Health and Life Profile Questionnaire for signs of emotional distress. If these are noted while the participant is completing the forms, (1) the interviewer encourages the participant to discontinue working on the HLP form and (2) and escorts her/him to the next workstation after allowing ample time for the participant to regain composure. (3) After the participant has gone to the next workstation, the interviewer notifies the person conducting the Medical Data Review.

It is anticipated that participants will occasionally express manifestations compatible with depressive symptoms, extreme exhaustion, or emotional distress in their responses to selected items. Certain responses to the following questions in the HLP questionnaire should lead to the notification of the person doing the Medical Data Review. After the participant leaves the HLP workstation, or during data inventory, the following questions and responses on the HLP form are reviewed. The items of special concern are underlined and should be called to the reviewer's attention if the responses are as shown in the second column.

<u>Items of Concern from HLP</u>	<u>Responses Indicative of Emotional Distress</u>
Part A: <u>Item 2</u>	8, 9, and/or 10
<u>Item 22</u>	A
Part B: Item 7	Y
Item 10	Y
Item 13	Y
<u>Item 16</u>	Y