QUALITY OF LIFE, SOCIAL SUPPORT, SOCIAL NETWORK

1   Background

The purpose of this form is to measure quality of life; it identifies a wide range of characteristics that describe an individual's ability to function and to derive satisfaction from life. It can be viewed as a measure of the burden of disease. Quality of life may be a risk factor or effect modifier of other risk factors for cardiovascular disease. Changes in the quality of life may also be an outcome of cardiovascular disease. Social relationships have been shown to constitute a major risk factor for health. The social support section ascertains how well the participants perceive they are supported. The perceived availability of social support will buffer the individual against the negative effects of significant life stressors. The Lubben Social Network Scale indicates how social support is provided.

2   Definitions

2.1   <u>Relatives</u> includes first- and second-degree relatives either by blood relationship
             or marriage. For example:
             Spouse
             Child
             Sibling
             Parent
             Aunt/uncle
             Cousin

2.2   <u>Scoring</u>

2.2.1   **<u>Social Support</u>**

The computer calculates the score based on an algorithm which totals the scores for all responses in questions 3 through 8. Total the values from 1 through 4 for all questions. Do not include Code "9 - Refused to answer" in the score. If each question is answered, the total score will be 0 to 24.

2.2.2   **<u>Social Network</u>**

The Lubben Social Network Score is obtained by adding the scores from each of the ten individual items. If each question is answered, the total score will be 0 to 50. Scores on each item are anchored between 0 and 5 to permit equal weighting of the ten items.

3   Methods

3.1   The Quality of Life, Social Support and Social Network form is administered by a

CHS certified interviewer at the following periodic intervals:

Initial Home Interview
First Follow-up (Surveillance) Clinic Visit
Second Follow-up (Year 4) Clinic Visit
Third Follow-up (Year 5) Clinic Visit

3.2   The questionnaire is divided into three sections discussed below.

3.2.1   <u>Introduction</u>

     <u>Script</u>: I have some questions to ask you about how you feel about your life and your health. There are no right or wrong answers. I am interested in your feelings and opinions.

3.2.2   <u>Perceived Health and Quality of Life</u>

■   Question 1 - Based on the responses on this card, how do you feel about life as a whole?

- Hand the participant Card 5-S which lists the valid responses.

- Read the response choices to the participant:
  1 - Delighted
  2 - Pleased
  3 - Mostly satisfied
  4 - Mostly dissatisfied
  5 - Unhappy
  6 - Terrible

- Ask the participant to tell you which response most appropriately describes his/her feeling about life as a whole. Check the response on the form. If the participant refuses to answer the question, check "Refused to answer".

■   Question 2 - I want to ask you about how satisfied you are with the meaning and purpose of your life. Here is a card; the scale goes from 1 for extremely satisfied to 10 for extremely dissatisfied. On this scale of 1 to 10, how satisfied are you with the meaning and purpose of your life?

- Hand the participant Card 6-S which lists the valid responses.
- Check the response on the form. If the participant refuses to answer the question, check "participant refused."

3.2.3   **Questions 3 through 8 -** <u>Social Support Scale</u>

<u>Script:</u> I am going to read you a series of statements about yourself and I would like you to answer with one of the responses on this card. The responses are: definitely true, probably true, probably false, definitely false.

-      Hand the participant Card 7-S. For each question below, check the participant's response. If participant refuses to answer the question, check "participant refused."

■   Question 3 - The first statement is: If I feel lonely, there are several people I can talk to.

-      Read the response choices to the participant:
  1 - Definitely true
  2 - Probably true
  3 - Probably false
  4 - Definitely false

-      Check the response on the form. If the participant refuses to answer the question, check "participant refused."

‡   Question 4 - The next statement is: I often meet or talk with family or friends.

-      **For** Questions 4 through 8, use your judgment and knowledge of the participant to decide whether to read the responses. If the participant hesitates or seems confused, or if you know that the participant cannot read the responses from the card, repeat the responses as often as you judge necessary.

■   Question 5 - The next statement is: If I were sick, I could easily find someone to help me with my daily chores.

■   Question 6 - The next statement is: When I need suggestions on how to deal with a personal problem, I know someone I can turn to.

■   Question 7 - The next statement is: There is at least one person I know whose advice I really trust.

■   Question 8 - The next statement is: If I had to go out of town for a few weeks, it would be difficult to find someone who would look after my home, for example the plants, pets, garden, etc.

3.2.4   **Questions 9 through 19 - The Social Network Scale**

<u>Script:</u> Now I would like to ask you some questions about your family and friends.

- Read each question from the form.

- Check the response on the form. If the participant refuses to answer the question, check "Refused to answer".

■ Question 9 - How many different relatives do you see or hear from at least once a month? Please include your spouse and in-laws.

- You may read the responses if you think appropriate. Response choices are:

  0-none
  1-one
  2-two
  3-three or four
  4-five to eight
  5-nine or more
  9-refused to answer

■ Question 10 - Tell me about the relative with whom you have the most contact. How often do you see or hear from that person?

- Spouse is included as a relative for this question.

- Read responses if you think appropriate. Response choices are:

  0-less than once a month
  1-once a month
  2-a few times a month
  3-weekly
  4-a few times a week
  5-daily
  9-refused to answer

■ Question 11 - How many relatives do you feel close to? That is, how many of them do you feel at ease with, can you talk to about private matters, or can you call on for help?

- Spouse is included. Response choices are the same as for Question 9.

■ Question 12 - How many close friends do you have? That is, friends with whom you feel at ease, can talk to about private matters or can call on for help.

- Response choices are the same as for Question 9.

■ Question 13 - How many of these friends do you see or hear from at least once a month?

- Response choices are the same as for Question 9.

■ Question 14 - Tell me about the friend with whom you have the most contact. How often do you see or hear from that person?

- Response choices are the same as for Question 10.

■ Question 15 - When you have an important decision to make, do you have someone you can talk to about it?

- Response choices are:

  1-yes
  0-no
  9-refused to answer.

- If the participant responds that s/he does not have difficult decisions to make, respond with the following probe:

  "If you had a difficult decision to make, do you have someone   you could talk to about it?"

- If participant answers "yes," ask:

Script: When you have an important decision to make, how often do you have someone to talk to about it?

- Read the first five response choices to the participant. The response choices are:

    5-always
    4-very often
    3-often
    2-sometimes

1-seldom
9-refused to answer

- NOTE: If the participant initially responds "yes," but then refuses to respond to query of "how often," check "participant refused."

■ Question 16 - When other people you know have an important decision to make, do they talk to you about it?

- Follow instructions for Question 15, reading response choices if you think necessary.

■ Question 17 - Does anybody rely on you to do something for them each day? For example: shopping, cooking dinner, doing repairs, cleaning house, providing child care, etc.

- Response choices for Question 17 are:

    0 - No
    5 - Yes
    9 - Participant refused

- If participant's response is "yes," check "Yes" and skip to question 19.

■ Question 18 - Do you help anybody with things like shopping, filling out forms, doing repairs, providing child care, etc.?

- Response choices are the same as for Question 17.
- If participant responds "yes," check Yes" and ask:

Script: How often: very often, often, sometimes, or seldom?

- NOTE: If the participant responds "yes" initially, but then refuses to respond to query of "how often", check "Participant refused".

■ Question 19 - Do you live alone or with other people?

- Response choices are:

  0-alone
  1-with other people

- If participant responds "with other people," ask:

Script: Who do you live with?

- Response choices are:

  5 - Spouse
  4 - Other relatives, in-laws, or friends
  1 - Unrelated individuals; for example, paid help, Board and Care Homes,
        or skilled nursing facilities.
  0 - Live alone
  9 - Refused to answer

- If the participant gives more than one answer (lists more than one of the
  choices), check the response choice with the highest numerical score.

Interviewer: When all questions on both the Quality of Life, Social Support, Social
Network form and the Stressful Life Events and Depression Scale have been answered,
evaluate the participant's responses by answering Questions A and B at the end of the
Quality of Life, Social Support, Social Network form BASED ON YOUR OWN BEST
JUDGEMENT.

■   Question A - On the whole, how well was the respondent able to answer the
      questions you asked?

  - Response choices are:

    1-very well
    2-fairly well
    3-not very well

■   Question B - How cooperative was the respondent in answering your questions?

  - Response choices are:

    1-very cooperative
    2-fairly cooperative
    3-not cooperative