



pathways
a study of
breast cancer
survivorship

Social Measures Self-Administered Baseline Questionnaire Parts 1-2

If you have any questions about this form please
call the Pathways Study Coordinating Center.
Toll-free number: 1-866-206-2979

INTERVIEWER ID:

DATE: / /
MONTH DAY YEAR

DOD RACIAL DISPARITIES STUDY CONSENT:

1 ☐ YES

0 ☐ NO

SELF-ADMINISTERED:

1 ☐ YES

0 ☐ NO

COMMENTS: _____

January 2007 Version

ENROLLMENT ID LABEL

STUDY ID BARCODE LABEL

FOR OFFICE USE:

CODER ID:

CODING DATE: _____

REVIEWER ID:

REVIEW DATE: _____

COMMENTS: _____

DATA ENTRY DATE: _____

COMMENTS: _____

SOCIAL MEASURES PART 1

The next sections ask various questions about your quality of life, how you feel about your medical care, and related issues. Some of these questions have been used in other studies and are standard questions. The first few questions ask about time constraints related to your health, and whether anyone depends on you for help.

SECTION A.

A1. How difficult is it for you to take time off when you are sick and/or need to get medical treatments?

- 1 ☐ Not difficult at all
- 2 ☐ A little difficult
- 3 ☐ Moderately difficult
- 4 ☐ Very difficult
- 8 ☐ DON'T KNOW/NOT APPLICABLE
- 9 ☐ REFUSED

A2. How difficult is it for you to get to appointments due to distance and/or lack of transportation?

- 1 ☐ Not difficult at all
- 2 ☐ A little difficult
- 3 ☐ Moderately difficult
- 4 ☐ Very difficult
- 8 ☐ DON'T KNOW/NOT APPLICABLE
- 9 ☐ REFUSED

A3. Does anyone at home depend on you for care or for help?

- 1 ☐ YES →
- 0 ☐ NO
- 8 ☐ DON'T KNOW/NOT APPLICABLE
- 9 ☐ REFUSED

A4. Who depends on you for care or for help? (Check all that apply)

- 1 ☐ Husband or partner
- 1 ☐ Mother or father or both
- 1 ☐ Children or grandchildren
- 1 ☐ Other relatives
- 1 ☐ Friends or neighbors
- 1 ☐ Other person (Please specify):

-
- 8 ☐ DON'T KNOW/NOT APPLICABLE
 - 9 ☐ REFUSED

CODE

SECTION C. (Continued)

During the past 7 days:	Not at all	A little bit	Some-what	Quite a bit	Very much	Not applicable
C9. I feel distant from my friends.	0	1	2	3	4	9
C10. I get emotional support from my family.	0	1	2	3	4	9
C11. I get support from my friends and neighbors.	0	1	2	3	4	9
C12. My family has accepted my illness.	0	1	2	3	4	9
C13. Family communication about my illness is poor.	0	1	2	3	4	9
C14. I feel close to my partner (or the person who is my main support).	0	1	2	3	4	9
C15. Have you been sexually active in the past year? (Check one) 0 ☐ NO 1 ☐ YES						
C16. IF YES: I was satisfied with my sex life (Circle number)	0	1	2	3	4	9
C17. Looking at the above eight questions, how much would you say your social/family well-being affects your quality of life? (Circle number)						
0 1 2 3 4 5 6 7 8 9 10 Not at all Very much						

During the past 7 days:	Not at all	A little bit	Some-what	Quite a bit	Very much	Not applicable
C18. I have confidence in my doctor(s).	0	1	2	3	4	9
C19. My doctor is available to answer my questions.	0	1	2	3	4	9
C20. Looking at the above two questions, how much would you say your relationship with your doctor affects your quality of life? (Circle number)						
0 1 2 3 4 5 6 7 8 9 10 Not at all Very much						

During the past 7 days:	Not at all	A little bit	Some-what	Quite a bit	Very much	Not applicable
C21. I feel sad.	0	1	2	3	4	9
C22. I am proud of how I am coping with my illness.	0	1	2	3	4	9
C23. I am losing hope in the fight against my illness.	0	1	2	3	4	9
C24. I feel nervous.	0	1	2	3	4	9
C25. I worry about dying.	0	1	2	3	4	9
C26. I worry that my condition will get worse.	0	1	2	3	4	9
C27. Looking at the above six questions, how much would you say your emotional well-being affects your quality of life? (Circle number)						
0 1 2 3 4 5 6 7 8 9 10 Not at all Very much						

SECTION C. (Continued)

During the past 7 days:	Not at all	A little bit	Some-what	Quite a bit	Very much	Not applicable
C28. I am able to work (include the work at home).	0	1	2	3	4	9
C29. My work (include work at home) is fulfilling.	0	1	2	3	4	9
C30. I am able to enjoy life.	0	1	2	3	4	9
C31. I have accepted my illness.	0	1	2	3	4	9
C32. I am sleeping well.	0	1	2	3	4	9
C33. I am enjoying the things I usually do for fun.	0	1	2	3	4	9
C34. I am content with the quality of my life right now.	0	1	2	3	4	9
C35. Looking at the above seven questions, how much would you say your functional well-being affects your quality of life? (Circle number)						
0 1 2 3 4 5 6 7 8 9 10 Not at all Very much						

During the past 7 days:	Not at all	A little bit	Some-what	Quite a bit	Very much	Not applicable
C36. I have been short of breath.	0	1	2	3	4	9
C37. I am self-conscious about the way I dress.	0	1	2	3	4	9
C38. One or both of my arms are swollen or tender.	0	1	2	3	4	9
C39. I feel sexually attractive.	0	1	2	3	4	9
C40. I am bothered by hair loss.	0	1	2	3	4	9
C41. I worry about the risk of cancer in other family members.	0	1	2	3	4	9
C42. I worry about the effect of stress on my illness.	0	1	2	3	4	9
C43. I am bothered by a change in weight.	0	1	2	3	4	9
C44. I am able to feel like a woman.	0	1	2	3	4	9
C45. I have felt embarrassed about having breast cancer.	0	1	2	3	4	9
C46. I have felt ashamed about my condition.	0	1	2	3	4	9
C47. I have felt stigmatized about having breast cancer.	0	1	2	3	4	9
C48. Looking at the above twelve questions, how much would you say your additional concerns affect your quality of life? (Circle number)						
0 1 2 3 4 5 6 7 8 9 10 Not at all Very much						

SECTION D.

Please indicate the degree to which you agree with how each of the following items represents your feelings.

	Strongly Agree	Agree	Neither Agree or Disagree	Disagree	Strongly Disagree
D1. I'm always optimistic about my future.	1	2	3	4	5
D2. In uncertain times, I usually expect the best.	1	2	3	4	5
D3. I always look on the bright side of things.	1	2	3	4	5
D4. If something can go wrong for me, it will.	1	2	3	4	5
D5. It's easy for me to relax.	1	2	3	4	5
D6. I hardly ever expect things to go my way.	1	2	3	4	5
D7. I enjoy my friends a lot.	1	2	3	4	5
D8. It's important for me to keep busy.	1	2	3	4	5
D9. I rarely count on good things happening to me.	1	2	3	4	5
D10. I'm a believer in the idea that "every cloud has a silver lining."	1	2	3	4	5
D11. I don't get upset too easily.	1	2	3	4	5
D12. Things never work out the way I want them to.	1	2	3	4	5

PLEASE CONTINUE TO
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SECTION E.

Next are some questions about the support that is available to you.

- E1. About how many close friends and close relatives do you have? These are people you feel at ease with and can talk to about what is on your mind. Please state a number.

NUMBER OF CLOSE FRIENDS OR RELATIVES

People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kind of support available to you if you need it? (Please circle the best response)

How much of the time do you have...	None of the time	A little of the time	Some of the time	Most of the time	All of the time
E2. Someone you can count on to listen to you when you need to talk?	1	2	3	4	5
E3. Someone to give you information to help you understand a situation?	1	2	3	4	5
E4. Someone to give you good advice about a crisis?	1	2	3	4	5
E5. Someone to confide in or talk to about yourself or your problems?	1	2	3	4	5
E6. Someone whose advice you really want?	1	2	3	4	5
E7. Someone to share your most private worries and fears with?	1	2	3	4	5
E8. Someone to turn to for suggestions about how to deal with a personal problem?	1	2	3	4	5
E9. Someone who understands your problems?	1	2	3	4	5
E10. Someone to help you if you were confined to bed?	1	2	3	4	5
E11. Someone to take you to the doctor if you needed it?	1	2	3	4	5
E12. Someone to prepare your meals if you were unable to do it yourself?	1	2	3	4	5
E13. Someone to help with daily chores if you were sick?	1	2	3	4	5
E14. Someone who shows you love and affection?	1	2	3	4	5
E15. Someone to love you and make you feel wanted?	1	2	3	4	5
E16. Someone who hugs you?	1	2	3	4	5
E17. Someone to have a good time with?	1	2	3	4	5
E18. Someone to get together with for relaxation?	1	2	3	4	5
E19. Someone to do something enjoyable with?	1	2	3	4	5
E20. Someone to do things with to help you get your mind off things?	1	2	3	4	5

SOCIAL MEASURES PART 2

SECTION F.

The following questions have to do with medical information that you have received. (Please circle the best response)

	Always	Often	Sometimes	Occasionally	Never
F1. How often do you have problems learning about your medical condition because of difficulty understanding written information?	1	2	3	4	5
F2. How often are you confident filling out medical forms by yourself?	1	2	3	4	5
F3. How often do you have someone help you read hospital materials?	1	2	3	4	5

F4. Overall, how would you rate your current understanding of breast cancer and its treatment?

- ☐ Excellent
☐ Very Good
☐ Good
☐ Fair
☐ Poor

SECTION G.

The following questions are about your experiences talking with your doctors over the past 12 months. (Please circle the best response)

	Never	Rarely	Sometimes	Usually	Always
G1. How often did doctors speak too fast?	1	2	3	4	5
G2. How often did doctors use words that were hard to understand?	1	2	3	4	5
G3. How often did doctors really find out what your concerns were?	1	2	3	4	5
G4. How often did doctors let you say what you thought was important?	1	2	3	4	5
G5. How often did doctors take your health concerns very seriously?	1	2	3	4	5
G6. How often did doctors explain your test results such as blood tests, x-rays, or cancer screening tests?	1	2	3	4	5
G7. How often did doctors clearly explain the results of your physical exam?	1	2	3	4	5

These questions are about how you and your medical doctors decide about your health care.

	Never	Rarely	Sometimes	Usually	Always
G8. How often did you and your doctor(s) work out a treatment plan together?	1	2	3	4	5
G9. If there were treatment choices, how often did doctors ask if you would like to help decide your treatment?	1	2	3	4	5

SECTION G. (Continued)

The next questions are about the personal interactions between you and your doctor(s). (Circle best response)

	Never	Rarely	Sometimes	Usually	Always
G10. How often were doctors concerned about your feelings?	1	2	3	4	5
G11. How often did doctors really respect you as a person?	1	2	3	4	5
G12. How often did doctors treat you as an equal?	1	2	3	4	5
G13. How often did doctors pay less attention to you because of your race or ethnicity?	1	2	3	4	5
G14. How often did you feel discriminated against by doctors because of your race or ethnicity?	1	2	3	4	5
G15. How often was the office staff rude to you?	1	2	3	4	5
G16. How often did the office staff talk down to you?	1	2	3	4	5
G17. How often did the office staff give you a hard time?	1	2	3	4	5
G18. How often did the office staff have a negative attitude toward you?	1	2	3	4	5

SECTION H.

Thinking about how much you trust your doctor, how strongly do you agree or disagree with the following statement:

	Strongly Agree	Agree	Not sure	Disagree	Strongly Disagree
H1. My doctor cares more about holding down costs than about doing what is needed for my health.	1	2	3	4	5
H2. All things considered, how much do you trust your doctor? (Please circle a number)	0 1 2 3 4 5 6 7 8 9 10 Not at all Completely				

SECTION I.

This next section lists a series of statements about the ways you might have felt or behaved recently. Please state how often you have felt this way during the past 7 days. (Please circle the best response).

During the past week:	Rarely or none of the time (<1 day/ week)	Some or a little of the time (1-2 days/ week)	Occasionally or a moderate amount of time (3-4 days/ week)	Most or all of the time (5-7 days/ week)
I1. I was bothered by things that usually don't bother me.	0	1	2	3
I2. I did not feel like eating; my appetite was poor.	0	1	2	3
I3. I felt that I could not shake off the blues even with help from my family or friends.	0	1	2	3
I4. I felt that I was just as good as other people.	0	1	2	3
I5. I had trouble keeping my mind on what I was doing.	0	1	2	3
I6. I felt depressed.	0	1	2	3
I7. I felt that everything I did was an effort.	0	1	2	3
I8. I felt hopeful about the future.	0	1	2	3
I9. I thought my life had been a failure.	0	1	2	3
I10. I felt fearful.	0	1	2	3
I11. My sleep was restless.	0	1	2	3
I12. I was happy.	0	1	2	3
I13. I talked less than usual.	0	1	2	3
I14. I felt lonely.	0	1	2	3
I15. People were unfriendly.	0	1	2	3
I16. I enjoyed life.	0	1	2	3
I17. I had crying spells.	0	1	2	3
I18. I felt sad.	0	1	2	3
I19. I felt that people disliked me.	0	1	2	3
I20. I could not get going.	0	1	2	3

SECTION J.

The following topics relate to problems that you may have experienced during the past 7 days. Please evaluate how much they stressed you. (Please circle the best response)

During the past week:	Not at all	Somewhat	Moderately so	Very much
J1. Health	1	2	3	4
J2. Money	1	2	3	4
J3. Job	1	2	3	4
J4. Family or marriage	1	2	3	4
J5. Other people	1	2	3	4
J6. Children	1	2	3	4
J7. Crime	1	2	3	4
J8. Police	1	2	3	4
J9. Love life	1	2	3	4
J10. Racial conflict	1	2	3	4

SECTION K.

This next section asks about how you and others like you are treated, and how you typically respond.

K1. If you feel you have been treated unfairly, do you usually: (please check the best response)

- 1 ☐ Accept it as a fact of life
 2 ☐ Try to do something about it

K2. If you have been treated unfairly, do you usually: (please check the best response)

- 1 ☐ Talk to other people about it
 2 ☐ Keep it to yourself

Have you ever experienced discrimination, been prevented from doing something, or been hassled or made to feel inferior in any of the following situations because of your race, ethnicity, or color? (Please check the best response)		
K3. At school?	1 ☐ Yes → 0 ☐ No	a. How many times did this happen? 1 ☐ Once 2 ☐ Two or three times 3 ☐ Four or more times
K4. Getting hired or getting a job?	1 ☐ Yes → 0 ☐ No	a. How many times did this happen? 1 ☐ Once 2 ☐ Two or three times 3 ☐ Four or more times

Have you ever experienced discrimination, been prevented from doing something, or been hassled or made to feel inferior in any of the following situations because of your race, ethnicity, or color?

(Please check the best response)

K5. At work?	1 ☐ Yes → 0 ☐ No	a. How many times did this happen? 1 ☐ Once 2 ☐ Two or three times 3 ☐ Four or more times
K6. Getting housing?	1 ☐ Yes → 0 ☐ No	a. How many times did this happen? 1 ☐ Once 2 ☐ Two or three times 3 ☐ Four or more times
K7. Getting medical care?	1 ☐ Yes → 0 ☐ No	a. How many times did this happen? 1 ☐ Once 2 ☐ Two or three times 3 ☐ Four or more times
K8. Getting service in a store or restaurant?	1 ☐ Yes → 0 ☐ No	a. How many times did this happen? 1 ☐ Once 2 ☐ Two or three times 3 ☐ Four or more times
K9. Getting credit, bank loans, or a mortgage?	1 ☐ Yes → 0 ☐ No	a. How many times did this happen? 1 ☐ Once 2 ☐ Two or three times 3 ☐ Four or more times
K10. On the street or in a public setting?	1 ☐ Yes → 0 ☐ No	a. How many times did this happen? 1 ☐ Once 2 ☐ Two or three times 3 ☐ Four or more times
K11. From the police or in the courts?	1 ☐ Yes → 0 ☐ No	a. How many times did this happen? 1 ☐ Once 2 ☐ Two or three times 3 ☐ Four or more times

K12. In the past 12 months, were you physically abused by being hit, slapped, pushed, shoved, or punched by a current or former spouse or intimate partner? (Please check the best response)

- 1 ☐ YES
 0 ☐ NO
 2 ☐ DON'T KNOW
 8 ☐ NOT APPLICABLE
 9 ☐ REFUSED

K13. In the past 12 months, were you verbally abused by being made fun of, severely criticized, told you were a stupid or worthless person, or threatened with harm to yourself, your possessions, or your pets by a current or former spouse or intimate partner? (Please check the best response)

1 ☐ YES

0 ☐ NO

2 ☐ DON'T KNOW

8 ☐ NOT APPLICABLE

9 ☐ REFUSED

SECTION L.

Cella D, Peterman A, Hudgens S, et al. Cancer 2003;98:822-831.

The next section has a list of physical symptoms that other women with breast cancer sometimes experience. By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

During the past 7 days:	Not at all	A little bit	Some-what	Quite a bit	Very much
L1. I have numbness or tingling in my hands.	0	1	2	3	4
L2. I have numbness or tingling in my feet.	0	1	2	3	4
L3. I feel discomfort in my hands.	0	1	2	3	4
L4. I feel discomfort in my feet.	0	1	2	3	4
L5. I have joint pain or muscle cramps.	0	1	2	3	4
L6. I feel weak all over.	0	1	2	3	4
L7. I have trouble hearing.	0	1	2	3	4
L8. I get a ringing or buzzing in my ears.	0	1	2	3	4
L9. I have trouble buttoning buttons.	0	1	2	3	4
L10. I have trouble feeling the shape of small objects when they are in my hand.	0	1	2	3	4
L11. I have trouble walking.	0	1	2	3	4
L12. I feel bloated.	0	1	2	3	4
L13. My hands are swollen.	0	1	2	3	4
L14. My legs or feet are swollen.	0	1	2	3	4
L15. I have pain in my fingertips.	0	1	2	3	4
L16. I am bothered by the way my hands or nails look.	0	1	2	3	4