



pathways

a study of
breast cancer
survivorship

Lymphedema Self-Administered Baseline Questionnaire

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

SELF-ADMINISTERED:

1 ☐ YES

0 ☐ NO

COMMENTS: _____

January 2008 Version

ENROLLMENT ID LABEL

STUDY ID BARCODE LABEL

FOR OFFICE USE:

REVIEWER ID:

REVIEW DATE: _____

CODER ID:

CODING DATE: _____

COMMENTS: _____

DATA ENTRY DATE: _____

COMMENTS: _____

SECTION A. LYMPHEDEMA SYMPTOMS

Lymphedema is the excessive swelling of the arm and/or hand due to fluid buildup following breast cancer surgery. The swelling is usually throughout the arm and/or hand and lasts for at least 1 month. The following questions ask about your experiences with lymphedema.

A1. Did you have breast cancer surgery?

- 1 ☐ YES →
 0 ☐ NO →
 8 ☐ DON'T KNOW →

**GO TO SECTION B
ON PAGE 6**

A2. What type(s) of surgery did you have?
Check all that apply.

- ☐ LUMPECTOMY
☐ MASTECTOMY
☐ AXILLARY LYMPH NODE DISSECTION
☐ SENTINEL LYMPH NODE DISSECTION
☐ OTHER (specify): _____
☐ DON'T KNOW

CODE

A3. Since your breast cancer surgery, has a health care professional told you that you had lymphedema?

- 1 ☐ YES
 0 ☐ NO
 8 ☐ DON'T KNOW

A4. Since your breast cancer surgery, was there a time when your arms or hands were different sizes from each other?

- 1 ☐ YES
 0 ☐ NO →
 8 ☐ DON'T KNOW →

GO TO THE TABLE ON PAGE 5

A5. Since your breast cancer surgery, where does/did the swelling occur? *Check all that apply.*

- ☐ HAND →
☐ UPPER ARM (ABOVE THE ELBOW) →
☐ LOWER ARM (BELOW THE ELBOW) →
☐ DON'T KNOW

A5a. Was the swelling on the same side that you had your surgery?

- 1 ☐ YES
 0 ☐ NO
 8 ☐ DON'T KNOW

A6. Since your breast cancer surgery, how frequently does/did the swelling occur?

- 1 ☐ CONSTANTLY
 2 ☐ OCCASIONALLY
 3 ☐ OTHER (specify): _____
 8 ☐ DON'T KNOW

CODE

M: ☐ A1 ☐ A2 ☐ A3 ☐ A4 ☐ A5 ☐ A5a ☐ A6

A7. Since your breast cancer surgery, does/did the swelling interfere with any of the following? *Check all that apply.*

- ☐ Clothes
- ☐ Exercise
- ☐ Your appearance
- ☐ Ability to do routine activities such as household chores
- ☐ Other (specify): _____
- ☐ The swelling did not interfere with any of the above.
- ☐ Don't know

CODE		
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A8. How would you describe this swelling?

- 1 ☐ MILD (when area is pressed by fingertips, the area indents and holds the indentation temporarily)
- 2 ☐ MODERATE (area has spongy consistency, and when pressed by fingertips, the area does not indent)
- 3 ☐ SEVERE (swelling is irreversible, the limb/hand is very large, and the tissue is hard and unresponsive)
- 8 ☐ DON'T KNOW

A9. How soon after your initial surgery did this swelling first occur? (Enter the number in the boxes in front of the time frame that best explains your situation.)

a. DAY(S) **OR** b. WEEK(S) **OR** c. MONTH(S)

☐ DON'T KNOW

A10. Do you believe the start of your swelling was related to any of the following? *Check all that apply.*

- ☐ Radiation treatment
- ☐ Breast reconstruction
- ☐ Infection or injury to arm/hand
- ☐ Weather changes
- ☐ General use of your arm
- ☐ Exercise
- ☐ Airplane travel
- ☐ Removal of lymph nodes
- ☐ Other (specify): _____
- ☐ The start of my swelling was not related to any of the above
- ☐ Don't know

CODE		
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M: ☐A7 ☐A8 ☐A9 ☐A10

A11. Do you continue to have swelling now?

- 1 ☐ YES
 0 ☐ NO
 8 ☐ DON'T KNOW

GO TO QUESTION A13 BELOW

A12. How long did your swelling last? (Enter the number in the boxes in front of the time frame that best describes your situation.)

- a. DAY(S) **OR** b. WEEK(S) **OR** c. MONTH(S)
☐ DON'T KNOW

A13. Did you/Will you seek treatment for your swelling?

- 1 ☐ YES
 0 ☐ NO
 8 ☐ DON'T KNOW

GO TO THE TABLE ON THE NEXT PAGE

A14. What type of treatment did you/will you receive for your swelling? *Check all that apply.*

- ☐ Compression therapy by machine
☐ Glove/Sleeve Compression/Garment
☐ Manual lymphatic drainage
☐ Bandaging technique
☐ Arm massage
☐ Other (specify): _____
☐ Don't know

CODE

PLEASE CONTINUE TO NEXT PAGE

M: ☐ A11 ☐ A12 ☐ A13 ☐ A14

Have you experienced any of these other lymphedema symptoms?

If Yes, check all that apply for location of symptom currently and/or previously experienced as well as how much the symptom distressed or bothered you.

Note: "Previously" experiencing a symptom refers to the period prior to your breast cancer surgery.

Symptom	A15. Have you experienced this symptom? <i>Check all that apply.</i>	A16. If currently experiencing symptom, at which location(s)? <i>Check all that apply.</i>	A17. If previously experienced symptom, at which location(s)? <i>Check all that apply.</i>	A18. How much does/did this symptom distress or bother you?	A19. Do you know or think that this symptom was caused by lymphedema or another health condition ?
a. Tenderness	☐ No → <i>Go to next symptom</i> ☐ Yes, currently ☐ Yes, previously	☐ Hand ☐ Upper arm ☐ Lower arm	☐ Hand ☐ Upper arm ☐ Lower arm	1 ☐ Not at all 2 ☐ A little 3 ☐ Moderately 4 ☐ Quite a bit	1 ☐ Lymphedema 2 ☐ Another health condition 3 ☐ Don't know
b. Numbness	☐ No → <i>Go to next symptom</i> ☐ Yes, currently ☐ Yes, previously	☐ Hand ☐ Upper arm ☐ Lower arm	☐ Hand ☐ Upper arm ☐ Lower arm	1 ☐ Not at all 2 ☐ A little 3 ☐ Moderately 4 ☐ Quite a bit	1 ☐ Lymphedema 2 ☐ Another health condition 3 ☐ Don't know
c. Tiredness, thickness, heaviness of hand or arm	☐ No → <i>Go to next symptom</i> ☐ Yes, currently ☐ Yes, previously	☐ Hand ☐ Upper arm ☐ Lower arm	☐ Hand ☐ Upper arm ☐ Lower arm	1 ☐ Not at all 2 ☐ A little 3 ☐ Moderately 4 ☐ Quite a bit	1 ☐ Lymphedema 2 ☐ Another health condition 3 ☐ Don't know
d. Puffiness	☐ No → <i>Go to next symptom</i> ☐ Yes, currently ☐ Yes, previously	☐ Hand ☐ Upper arm ☐ Lower arm	☐ Hand ☐ Upper arm ☐ Lower arm	1 ☐ Not at all 2 ☐ A little 3 ☐ Moderately 4 ☐ Quite a bit	1 ☐ Lymphedema 2 ☐ Another health condition 3 ☐ Don't know
e. Difficulty in seeing knuckles or veins	☐ No → <i>Go to next symptom</i> ☐ Yes, currently ☐ Yes, previously	☐ Hand ☐ Upper arm ☐ Lower arm	☐ Hand ☐ Upper arm ☐ Lower arm	1 ☐ Not at all 2 ☐ A little 3 ☐ Moderately 4 ☐ Quite a bit	1 ☐ Lymphedema 2 ☐ Another health condition 3 ☐ Don't know
f. Pain	☐ No → <i>Go to next symptom</i> ☐ Yes, currently ☐ Yes, previously	☐ Hand ☐ Upper arm ☐ Lower arm	☐ Hand ☐ Upper arm ☐ Lower arm	1 ☐ Not at all 2 ☐ A little 3 ☐ Moderately 4 ☐ Quite a bit	1 ☐ Lymphedema 2 ☐ Another health condition 3 ☐ Don't know

M: ☐ A15a ☐ A15b ☐ A15c ☐ A15d ☐ A15e ☐ A15f
☐ A16a ☐ A16b ☐ A16c ☐ A16d ☐ A16e ☐ A16f
☐ A17a ☐ A17b ☐ A17c ☐ A17d ☐ A17e ☐ A17f
☐ A18a ☐ A18b ☐ A18c ☐ A18d ☐ A18e ☐ A18f
☐ A19a ☐ A19b ☐ A19c ☐ A19d ☐ A19e ☐ A19f

SECTION B. LYMPHEDEMA RESOURCES AND EDUCATION

The following questions will ask about your level of **lymphedema** knowledge and awareness.

B1. Have you received any resources for information about lymphedema from Kaiser Permanente?

1 ☐ YES

0 ☐ NO

8 ☐ DON'T KNOW

GO TO QUESTION B5 ON NEXT PAGE

B2. What types of resources did you receive from Kaiser Permanente? *Check all that apply.*

☐ Brochures, articles, books, or other written materials

☐ Support groups, counseling

☐ Video or audio tape

☐ Other (specify): _____

☐ Don't know

CODE

B3. From whom did you hear about these Kaiser Permanente resources? *Check all that apply.*

☐ Surgeon

☐ Oncologist

☐ Nurse

☐ Breast care coordinator

☐ Physical therapist

☐ Other (specify): _____

☐ Don't know

CODE

B4. If you were ever diagnosed with lymphedema, which Kaiser Permanente resources did you utilize? *Check all that apply.*

☐ I was not diagnosed with lymphedema

☐ Brochures, articles, books, or other written materials

☐ Support groups, counseling

☐ Video or audio tape

☐ Other (specify): _____

☐ Don't know

CODE

M: ☐ B1 ☐ B2 ☐ B3 ☐ B4 ☐ B5

B5. Were you informed at any time during your breast cancer care about the following lymphedema risk reduction practices? *Check all that apply.*

☐ I was not informed about any lymphedema risk reduction practices.

☐ Avoidance of trauma/injury

Examples:

- Keep arm and/or hand clean and dry
- Apply moisturizer daily to prevent chapping/chaffing of skin
- Attention to nail care
- Protect exposed skin with sunscreen and insect repellent
- Use care with razors
- Avoid punctures such as injections and blood draws
- Wear gloves while doing activities that may cause skin injury

☐ Prevention of infection

Examples:

- If scratches/punctures to skin occur, wash with soap and water, apply antibiotics
- If a rash, itching, redness, pain, increased skin temperature, fever or flu-like symptoms occur, contact your physician immediately

☐ Avoidance of arm constriction

Examples:

- If possible, avoid having blood pressure taken on the at risk arm
- Wear loose fitting jewelry and clothing

☐ Exercise of the affected arm

Examples:

- Gradually build up the duration and intensity of any activity or exercise
- Take frequent rest periods during activity to allow for limb recovery
- Monitor the arm and/or hand during and after activity for any physical change
- Maintain optimal weight

☐ Proper fit and use of compression garments

- Should be well-fitting
- Use for strenuous activities such as weight lifting, prolonged standing, running
- Wear for air travel

☐ Avoid temperature extremes

- Avoid exposure to extreme cold
- Avoid prolonged (> 15 minutes) of exposure to heat, specially hot tubs and saunas
- Avoid immersing limb in water temperatures above 102°F(39°C)

☐ Other (specify): _____

☐ Don't know

CODE

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THANK YOU FOR COMPLETING THIS QUESTIONNAIRE!