



The Royal College of Surgeons of England

Questionnaire for women who have had breast reconstruction surgery

| | | | | | | | | | |
|--|--|--|--|--|--|--|--|--|--|
| | | | | | | | | | |
|--|--|--|--|--|--|--|--|--|--|

What is this survey about?

We are writing to you on behalf of the National Mastectomy and Breast Reconstruction Audit. This audit is being carried out by the Royal College of Surgeons of England and the NHS Information Centre. It aims to improve the care provided to those women diagnosed with breast cancer or DCIS (ductal carcinoma in situ).

While in hospital about eighteen months ago, you kindly agreed to receive a questionnaire to assess the results of your surgery.

We would like to find out about your experiences and quality of life after surgery.

Some women undergo breast reconstruction with or after mastectomy surgery, although many do not. According to our records you have had a breast reconstruction, and therefore this questionnaire relates mainly to your experiences after reconstruction.

Your answers will help us to improve the care provided to all women who have this type of surgery, and we would very much appreciate your help in achieving this goal.

Who should complete the questionnaire?

The questions should be answered by the person named on the front of the envelope.

Completing the questionnaire

Please answer each question using a black or blue pen. Don't worry if you make a mistake – simply cross out the mistake and mark the correct answer. Please do not write your name or address anywhere on the questionnaire. Please return the questionnaire in the enclosed addressed envelope. You do not have to use a stamp as the postage is already paid.

Questions or help?

If you have any questions, please call the helpline on 0207 869 6619.

Taking part in this survey is voluntary. Your answers will be treated in confidence, and will not be seen by the doctors and nurses involved in your care. We will follow the standards set out in the Data Protection Act (1998) throughout our work.

Section 1: Dates

Q1. Please confirm your date of birth (day, month, and year):

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| d | d | m | m | y | y | y | y |
|---|---|---|---|---|---|---|---|

Q2. Please confirm the date on which your breast reconstruction operation took place (day, month and year):

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| d | d | m | m | y | y | y | y |
|---|---|---|---|---|---|---|---|

Q3. Please record the date on which you completed this form (day, month, and year):

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| d | d | m | m | y | y | y | y |
|---|---|---|---|---|---|---|---|

Section 2: Your current quality of life

Q4. With your breasts in mind, in the past 2 weeks, how satisfied or dissatisfied have you been with:

| | Very dissatisfied | Somewhat dissatisfied | Somewhat satisfied | Very satisfied |
|---|-------------------|-----------------------|--------------------|----------------|
| a. How you look in the mirror <u>clothed</u> ? | 1 | 2 | 3 | 4 |
| b. The shape of your reconstructed breast when you are wearing a bra? | 1 | 2 | 3 | 4 |
| c. How normal you feel in your clothes? | 1 | 2 | 3 | 4 |
| d. The size of your reconstructed breast? | 1 | 2 | 3 | 4 |
| e. Being able to wear clothing that is more fitted? | 1 | 2 | 3 | 4 |
| f. How your breasts (unclothed) are lined up in relation to each other? | 1 | 2 | 3 | 4 |
| g. How comfortably your bras fit? | 1 | 2 | 3 | 4 |
| h. The softness of your reconstructed breast? | 1 | 2 | 3 | 4 |
| i. How equal in size your breasts are to each other (unclothed)? | 1 | 2 | 3 | 4 |
| j. How natural your reconstructed breast looks (unclothed)? | 1 | 2 | 3 | 4 |
| k. How naturally your reconstructed breast sits / hangs (unclothed)? | 1 | 2 | 3 | 4 |
| l. How your reconstructed breast feels to touch? | 1 | 2 | 3 | 4 |
| m. How much your reconstructed breast feels like a natural part of your body? | 1 | 2 | 3 | 4 |
| n. How closely matched your breasts are to each other (unclothed)? | 1 | 2 | 3 | 4 |
| o. How your reconstructed breast looks now compared to before you had any breast surgery? | 1 | 2 | 3 | 4 |
| p. How you look in the mirror <u>unclothed</u> ? | 1 | 2 | 3 | 4 |

This question is about breast reconstruction using an IMPLANT. If you do not have an implant please skip to question 6.

Q5. In the past 2 weeks, how satisfied or dissatisfied have you been with:

| | Very dissatisfied | Somewhat dissatisfied | Somewhat satisfied | Very satisfied |
|--|-------------------|-----------------------|--------------------|----------------|
| a. The amount of rippling (wrinkling or creasing) of your implant that you can <u>see</u> ? | 1 | 2 | 3 | 4 |
| b. The amount of rippling (wrinkling or creasing) of your implant that you can <u>feel</u> ? | 1 | 2 | 3 | 4 |

Q6. This question asks how you feel about the outcome of your breast reconstruction surgery:

| | Disagree | Somewhat Agree | Definitely Agree |
|---|----------|----------------|------------------|
| a. Having reconstruction is much better than the alternative of having no breast. | 1 | 2 | 3 |
| b. I would encourage other women in my situation to have breast reconstruction surgery. | 1 | 2 | 3 |
| c. I would do it again. | 1 | 2 | 3 |
| d. I have no regrets about having the reconstruction surgery. | 1 | 2 | 3 |
| e. Having the reconstruction surgery changed my life for the better. | 1 | 2 | 3 |
| f. The outcome perfectly matched my expectations. | 1 | 2 | 3 |
| g. It turned out exactly as I had planned. | 1 | 2 | 3 |

Q7. With your breasts in mind, in the past 2 weeks, how often have you felt:

| | None of the time | A little of the time | Some of the time | Most of the time | All of the time |
|---|------------------|----------------------|------------------|------------------|-----------------|
| a. Confident in a social setting? | 1 | 2 | 3 | 4 | 5 |
| b. Emotionally able to do the things that you want to do? | 1 | 2 | 3 | 4 | 5 |
| c. Emotionally healthy? | 1 | 2 | 3 | 4 | 5 |
| d. Of equal worth to other women? | 1 | 2 | 3 | 4 | 5 |
| e. Self-confident? | 1 | 2 | 3 | 4 | 5 |
| f. Feminine in your clothes? | 1 | 2 | 3 | 4 | 5 |
| g. Accepting of your body? | 1 | 2 | 3 | 4 | 5 |
| h. Normal? | 1 | 2 | 3 | 4 | 5 |
| i. Like other women? | 1 | 2 | 3 | 4 | 5 |
| j. Attractive? | 1 | 2 | 3 | 4 | 5 |

Q8. This question is about your sex-life. If you would prefer not to answer this question please tick this box and move on to question 9.

Thinking of your sexuality, since your breast reconstruction, how often do you generally feel:

| | None of the time | A little of the time | Some of the time | Most of the time | All of the time | Not Applicable |
|---|------------------|----------------------|------------------|------------------|-----------------|----------------|
| a. Sexually attractive in your clothes? | 1 | 2 | 3 | 4 | 5 | N/A |
| b. Comfortable / at ease during sexual activity? | 1 | 2 | 3 | 4 | 5 | N/A |
| c. Confident sexually? | 1 | 2 | 3 | 4 | 5 | N/A |
| d. Satisfied with your sex-life? | 1 | 2 | 3 | 4 | 5 | N/A |
| e. Confident sexually about how your breasts look when <u>unclothed</u> ? | 1 | 2 | 3 | 4 | 5 | N/A |
| f. Sexually attractive when <u>unclothed</u> ? | 1 | 2 | 3 | 4 | 5 | N/A |

Q9. In the past 2 weeks, how often have you experienced:

| | None of the time | A little of the time | Some of the time | Most of the time | All of the time |
|--|------------------|----------------------|------------------|------------------|-----------------|
| a. Neck pain? | 1 | 2 | 3 | 4 | 5 |
| b. Upper back pain? | 1 | 2 | 3 | 4 | 5 |
| c. Shoulder pain? | 1 | 2 | 3 | 4 | 5 |
| d. Arm pain? | 1 | 2 | 3 | 4 | 5 |
| e. Rib pain? | 1 | 2 | 3 | 4 | 5 |
| f. Pain in the muscles of your chest? | 1 | 2 | 3 | 4 | 5 |
| g. Difficulty lifting or moving your arms? | 1 | 2 | 3 | 4 | 5 |
| h. Difficulty sleeping because of discomfort in your breast area? | 1 | 2 | 3 | 4 | 5 |
| i. Tightness in your breast area? | 1 | 2 | 3 | 4 | 5 |
| j. Pulling in your breast area? | 1 | 2 | 3 | 4 | 5 |
| k. A nagging feeling in your breast area? | 1 | 2 | 3 | 4 | 5 |
| l. Tenderness in your breast area? | 1 | 2 | 3 | 4 | 5 |
| m. Sharp pains in your breast area? | 1 | 2 | 3 | 4 | 5 |
| n. Shooting pains in your breast area? | 1 | 2 | 3 | 4 | 5 |
| o. An aching feeling in your breast area? | 1 | 2 | 3 | 4 | 5 |
| p. A throbbing feeling in your breast area? | 1 | 2 | 3 | 4 | 5 |
| q. Swelling (lymphoedema) of the arm on the side that you had your mastectomy surgery? | 1 | 2 | 3 | 4 | 5 |

The following two questions are about reconstruction using skin and muscle from your back area. If you did not have this type of surgery, please skip to question 12.

Q10. In the past 2 weeks, with your back in mind, how often have you been bothered by:

| | None of the time | A little of the time | Some of the time | Most of the time | All of the time |
|---|------------------|----------------------|------------------|------------------|-----------------|
| a. How your back looks? | 1 | 2 | 3 | 4 | 5 |
| b. The shape (contour) of your back? | 1 | 2 | 3 | 4 | 5 |
| c. The sides of your back not matching? | 1 | 2 | 3 | 4 | 5 |
| d. How your back <u>scar</u> looks? | 1 | 2 | 3 | 4 | 5 |
| e. The <u>location</u> of your back scar? | 1 | 2 | 3 | 4 | 5 |
| f. The <u>length</u> of your back scar? | 1 | 2 | 3 | 4 | 5 |
| g. How noticeable your back scar is to others? | 1 | 2 | 3 | 4 | 5 |
| h. Having to wear certain clothes in order to <u>hide</u> your back scar? | 1 | 2 | 3 | 4 | 5 |
| i. <u>Not</u> being able to wear certain clothes because of your back scar (e.g. backless dress, bathing suit)? | 1 | 2 | 3 | 4 | 5 |

Q11. In the past 2 weeks, with your back and shoulder area in mind, how often have you experienced:

| | None of the time | A little of the time | Some of the time | Most of the time | All of the time |
|---|------------------|----------------------|------------------|------------------|-----------------|
| a. Back pain? | 1 | 2 | 3 | 4 | 5 |
| b. Shoulder pain? | 1 | 2 | 3 | 4 | 5 |
| c. An aching feeling in your <u>back</u> area? | 1 | 2 | 3 | 4 | 5 |
| d. An aching feeling in your <u>shoulder</u> area? | 1 | 2 | 3 | 4 | 5 |
| e. Shoulder stiffness? | 1 | 2 | 3 | 4 | 5 |
| f. Tightness when you stretch your arm? | 1 | 2 | 3 | 4 | 5 |
| g. A pulling feeling in your back? | 1 | 2 | 3 | 4 | 5 |
| h. Weakness in your arm? | 1 | 2 | 3 | 4 | 5 |
| i. Difficulty <u>lifting</u> heavy objects (e.g. large bag of groceries)? | 1 | 2 | 3 | 4 | 5 |
| j. Difficulty <u>carrying</u> heavy objects (e.g. large bag of groceries)? | 1 | 2 | 3 | 4 | 5 |
| k. Difficulty <u>reaching</u> for objects (e.g. taking something down from a high shelf)? | 1 | 2 | 3 | 4 | 5 |
| l. Difficulty doing activities with your arms <u>outstretched</u> (e.g. vacuuming, shoveling)? | 1 | 2 | 3 | 4 | 5 |
| m. Difficulty doing activities with your arms <u>above your head</u> (e.g. doing up dress zipper, styling your hair)? | 1 | 2 | 3 | 4 | 5 |
| n. Difficulty doing activities that <u>repeatedly</u> use shoulder and back muscles (e.g. throwing a ball, playing tennis, swimming)? | 1 | 2 | 3 | 4 | 5 |

The following three questions are about reconstruction using skin and fat from your abdomen / tummy area. If you did not have this type of surgery, please skip to question 15.

Q12. In the past 2 weeks, with your abdomen (tummy area) in mind, how often have you experienced:

| | None of the time | A little of the time | Some of the time | Most of the time | All of the time |
|--|------------------|----------------------|------------------|------------------|-----------------|
| a. Difficulty sitting up because of abdominal muscle weakness (e.g. getting out of bed)? | 1 | 2 | 3 | 4 | 5 |
| b. Difficulty doing everyday activities because of abdominal muscle weakness (e.g. making your bed)? | 1 | 2 | 3 | 4 | 5 |
| c. Abdominal discomfort? | 1 | 2 | 3 | 4 | 5 |
| d. Abdominal bloating? | 1 | 2 | 3 | 4 | 5 |
| e. Abdominal bulging? | 1 | 2 | 3 | 4 | 5 |
| f. Tightness in your abdomen? | 1 | 2 | 3 | 4 | 5 |
| g. Pulling in your abdomen? | 1 | 2 | 3 | 4 | 5 |
| h. Lower back pain? | 1 | 2 | 3 | 4 | 5 |

Q13. In the past 2 weeks, how satisfied or dissatisfied have you been with:

| | Very dissatisfied | Somewhat dissatisfied | Somewhat satisfied | Very satisfied |
|---|-------------------|-----------------------|--------------------|----------------|
| a. How your abdomen looks? | 1 | 2 | 3 | 4 |
| b. The position of your navel (belly button)? | 1 | 2 | 3 | 4 |
| c. How your abdominal scars look? | 1 | 2 | 3 | 4 |

Q14. In the past 2 weeks, how satisfied or dissatisfied have you been with:

| | Very dissatisfied | Somewhat dissatisfied | Somewhat satisfied | Very satisfied |
|---|-------------------|-----------------------|--------------------|----------------|
| a. How your abdomen <u>feels</u> now compared to before your surgery? | 1 | 2 | 3 | 4 |
| b. How your abdomen <u>looks</u> now compared to before your surgery? | 1 | 2 | 3 | 4 |

Q15. Below is a list of normal day to day activities. Please indicate how true each statement has been for you in the past 2 weeks.

| | Not at all | A little | A great deal |
|--|------------|----------|--------------|
| a. I need help using the telephone | 1 | 2 | 3 |
| b. I need help getting to places beyond walking distance | 1 | 2 | 3 |
| c. I need help grocery shopping | 1 | 2 | 3 |
| d. I need help preparing meals | 1 | 2 | 3 |
| e. I need help doing housework or DIY jobs | 1 | 2 | 3 |
| f. I need help doing laundry | 1 | 2 | 3 |
| g. I need help taking medication | 1 | 2 | 3 |
| h. I need help washing myself and dressing myself | 1 | 2 | 3 |

Section 3: Your cancer treatments

Q16. In the time since your mastectomy surgery have your doctors or nurses told you that the cancer or ductal carcinoma in situ (DCIS) has come back?

Yes

No

Q17. Have you had the following treatments since your mastectomy surgery?

| | Yes | No |
|--|--------------------------|--------------------------|
| a. Radiotherapy | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Chemotherapy | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Hormone drug therapy (e.g. tamoxifen, arimidex) | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Monoclonal antibody therapy (e.g. herceptin) | <input type="checkbox"/> | <input type="checkbox"/> |

Q18. Have you had the following procedures since your breast reconstruction surgery?

| | Yes | No |
|---|--------------------------|--------------------------|
| a. Nipple reconstruction | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Tattooing of areola (darker area around nipple) | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Exchange of expander for a fixed volume implant | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Exchange of expander or implant for a flap of your own tissue | <input type="checkbox"/> | <input type="checkbox"/> |
| e. Lipofilling (fat injection) or liposuction (fat removal) to improve the shape of your reconstructed breast | <input type="checkbox"/> | <input type="checkbox"/> |
| f. Implant or expander inserted into other breast to improve symmetry | <input type="checkbox"/> | <input type="checkbox"/> |
| g. Reduction in size or volume of other breast to improve symmetry | <input type="checkbox"/> | <input type="checkbox"/> |
| h. Reduction of skin of other breast (mastopexy or lift) to improve symmetry | <input type="checkbox"/> | <input type="checkbox"/> |
| i. Other (please specify below) | <input type="checkbox"/> | <input type="checkbox"/> |

Section 4: Your overall experience

Q19. Overall, how would you describe the results of your operation?

- Excellent
- Very good
- Good
- Fair
- Poor

Q20. Overall, how satisfied are you with the options you have been given about breast reconstruction surgery since the time of your original diagnosis?

- Very satisfied
- Somewhat satisfied
- Somewhat dissatisfied
- Very dissatisfied

Thank you for answering these questions.

Your answers will help us to improve the quality of care for all women undergoing mastectomy and breast reconstruction surgery in future.

Please return the questionnaire to the audit team in the enclosed addressed envelope.

You do not need to pay any postage on this envelope.

NHS

The
Information
Centre

for health and social care