



The Royal College of Surgeons of England

# Questionnaire for women who have recently had breast reconstruction surgery

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## **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 three months ago, you kindly agreed to receive a questionnaire to assess your satisfaction with surgery.

We would like to find out about how satisfied you were with the information, choices and care you received. We would also like to ask you about your experiences after discharge from hospital.

Some women undergo breast reconstruction at the time of their mastectomy, although many do not. According to our records you waited some time before you had breast reconstruction surgery, 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
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**Q2. Please confirm the date on which the mastectomy for the breast you recently had reconstructed took place (day, month and year):**

d	d	m	m	y	y	y	y
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**Q3. Please confirm the date on which your recent breast reconstruction operation took place (day, month and year):**

d	d	m	m	y	y	y	y
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**Q4. Please record the date on which you completed this form (day, month, and year):**

d	d	m	m	y	y	y	y
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## Section 2: Satisfaction with the information you were given by the people treating you

**Q5. How much information about breast reconstruction surgery was given to you before your operation?**

- Not enough
- The right amount
- Too much
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**Q6. Did you receive information about the benefits and risks of breast reconstruction in any of the following ways?**

	Yes	No
a. Discussion with a surgeon	<input type="checkbox"/>	<input type="checkbox"/>
b. Discussion with a breast care nurse	<input type="checkbox"/>	<input type="checkbox"/>
c. Written information (e.g. an information leaflet)	<input type="checkbox"/>	<input type="checkbox"/>
d. Pictures of what your breast area might look like after reconstruction	<input type="checkbox"/>	<input type="checkbox"/>

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**Q7. How satisfied or dissatisfied were you with the information you received about:**

	Very dissatisfied	Somewhat dissatisfied	Somewhat satisfied	Very satisfied
a. How the breast reconstruction surgery was to be done?	1	2	3	4
b. Healing and recovery time?	1	2	3	4
c. Possible complications?	1	2	3	4
d. The options you were given regarding types of breast reconstruction?	1	2	3	4
e. Having a breast reconstruction at the same time as your mastectomy (immediate reconstruction) versus having it later (delayed reconstruction)?	1	2	3	4
f. How long the process of breast reconstruction would take from start to finish?	1	2	3	4
g. What size you could expect your breasts to be after reconstructive surgery?	1	2	3	4
h. How much pain to expect during recovery?	1	2	3	4
i. What you could expect your breasts to look like after surgery?	1	2	3	4
j. How long after reconstruction surgery it would take to feel like yourself / feel normal again?	1	2	3	4
k. How the surgery could affect future breast cancer screening (e.g. mammograms)?	1	2	3	4
l. Lack of sensation in your reconstructed breast and nipple?	1	2	3	4
m. What other women experience with their breast reconstruction surgery?	1	2	3	4
n. What the scars would look like?	1	2	3	4

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### Section 3: Choices about breast reconstruction

**Q8. Before your recent breast reconstruction operation, were you given any choices about the type of breast reconstruction you could have?**

Yes

No

If No please ignore question 9 and move onto question 10.

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**Q9. If you answered Yes to question 8, how satisfied or dissatisfied are you with the choices you were given about breast reconstruction?**

Very dissatisfied

Somewhat dissatisfied

Somewhat satisfied

Very satisfied

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**Q10. We are interested in why some women do not have breast reconstruction after their mastectomy, so that we can better understand how they feel about this operation.**

**To help with this, we would like to know why you did not have your breast reconstructed at the time of your mastectomy, which we will refer to as immediate breast reconstruction from now on.**

**We understand that there may be lots of reasons why you did not have an immediate breast reconstruction.**

**At the time of your mastectomy, were the following true or false?**

	True	False
a. I was given no information about immediate breast reconstruction	<input type="checkbox"/>	<input type="checkbox"/>
b. I was not offered the option of immediate breast reconstruction	<input type="checkbox"/>	<input type="checkbox"/>
c. My doctors/nurses told me that immediate breast reconstruction was not an option because of my other health problems	<input type="checkbox"/>	<input type="checkbox"/>
d. My doctors/nurses told me I should wait for some time after the mastectomy before having a breast reconstruction	<input type="checkbox"/>	<input type="checkbox"/>
e. I was told that immediate breast reconstruction was not available at all at the hospital where I had my mastectomy	<input type="checkbox"/>	<input type="checkbox"/>
f. I was told that my preferred type of immediate breast reconstruction operation was not available at the hospital where I had my mastectomy	<input type="checkbox"/>	<input type="checkbox"/>
g. I was offered the option of immediate breast reconstruction, but I chose not to have it	<input type="checkbox"/>	<input type="checkbox"/>

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**Q11. If you chose not to accept the offer of immediate breast reconstruction please answer this question. Otherwise, please move onto question 12.**

**Why did you choose not to have immediate breast reconstruction?**

	Agree	Disagree
a. My cancer treatment was my sole priority	<input type="checkbox"/>	<input type="checkbox"/>
b. I was not concerned with how my breast area would look after mastectomy.	<input type="checkbox"/>	<input type="checkbox"/>
c. I did not feel as though I knew enough about the immediate breast reconstruction.	<input type="checkbox"/>	<input type="checkbox"/>
d. I did not have enough time to decide about having an immediate breast reconstruction.	<input type="checkbox"/>	<input type="checkbox"/>
e. I was worried about the length of time needed to recover after an immediate breast reconstruction.	<input type="checkbox"/>	<input type="checkbox"/>
f. I was worried about the complications that could happen after an immediate breast reconstruction.	<input type="checkbox"/>	<input type="checkbox"/>

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#### Section 4: Managing your pain

**Q12. How would you describe the pain you experienced in the first 24 hours after your breast reconstruction operation?**

- No pain at all
  - Mild pain
  - Moderate pain
  - Severe pain
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**Q13. How would you describe the pain you experienced in the first week after your breast reconstruction operation?**

- No pain at all
  - Mild pain
  - Moderate pain
  - Severe pain
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**Q14. Do you think the hospital staff did everything they could to help control your pain?**

- Yes, definitely
- Yes, to some extent
- No
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**Section 5: Your experiences after surgery**

**Q15. Since you were discharged from hospital, have you had any of the following problems?**

	Yes	No
a. Bleeding that required you to have a blood transfusion or more surgery	<input type="checkbox"/>	<input type="checkbox"/>
b. A wound in your breast, armpit, abdomen, buttock or thigh that opened up and required you to have more surgery	<input type="checkbox"/>	<input type="checkbox"/>
c. A wound infection that required you to have antibiotics	<input type="checkbox"/>	<input type="checkbox"/>
d. Some of the breast skin that remained after your mastectomy turned dark and died	<input type="checkbox"/>	<input type="checkbox"/>
e. Pain or tenderness in your chest, arm, armpit, back, abdomen, buttock or thigh that has still not gone away	<input type="checkbox"/>	<input type="checkbox"/>
f. Numbness in your chest, arm, armpit, back, abdomen, buttock or thigh that has still not gone away	<input type="checkbox"/>	<input type="checkbox"/>
g. Fluid (seroma) collecting in your breast, armpit, back, abdomen, buttock or thigh area that required removal with a needle or drain	<input type="checkbox"/>	<input type="checkbox"/>
h. Swelling (lymphoedema) of the arm on the side that you had your surgery	<input type="checkbox"/>	<input type="checkbox"/>
i. Difficulty moving your shoulder and arm on the side that you had your surgery	<input type="checkbox"/>	<input type="checkbox"/>
j. A blood clot in your legs (deep venous thrombosis) that required your blood to be thinned (anticoagulation) with injections or tablets	<input type="checkbox"/>	<input type="checkbox"/>
k. A blood clot in your lungs (pulmonary embolus)	<input type="checkbox"/>	<input type="checkbox"/>
l. A heart attack (acute myocardial infarction)	<input type="checkbox"/>	<input type="checkbox"/>
m. Other (please specify below)	<input type="checkbox"/>	<input type="checkbox"/>

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**Q16. Did you have a breast reconstruction that used an implant?**

Yes

No

If No please ignore question 17 and move onto question 18.

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**Q17. If you answered Yes to question 16, did you have any problems or complications since you were discharged from hospital that meant your implant had to be removed?**

Yes

No

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**Q18. Did you have a breast reconstruction that used your own tissue (a flap)?**

Yes

No

If No please ignore question 19 and move onto question 20.

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**Q19. If you answered Yes to question 18, have any of the following happened since you were discharged from hospital?**

	Yes	No
a. Part of your flap turned dark and died	<input type="checkbox"/>	<input type="checkbox"/>
b. All of your flap turned dark and died	<input type="checkbox"/>	<input type="checkbox"/>
c. You had an operation to remove some or all of your flap	<input type="checkbox"/>	<input type="checkbox"/>
d. A hernia (weakness or bulge) formed in the area from which your flap was taken	<input type="checkbox"/>	<input type="checkbox"/>
e. You had other problems in the area from which your flap was taken	<input type="checkbox"/>	<input type="checkbox"/>

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**Q20. Did you receive psychological support or counselling from a healthcare professional after your surgery?**

Yes

No

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**Q21. Did you see a physiotherapist after your surgery?**

Yes

No

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**Q22. Did you use a lymphoedema service after your surgery?**

Yes

No

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**Q23. Since you were discharged, have you been readmitted to hospital for any unplanned further treatment or surgery related to your breast reconstruction?**

Yes

No

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**Q24. Have you had the following treatments since your breast reconstruction surgery?**

	Yes	No
a. Hormone drug therapy (e.g. tamoxifen)	<input type="checkbox"/>	<input type="checkbox"/>
b. Specialist palliative care	<input type="checkbox"/>	<input type="checkbox"/>
c. Other reconstructive procedure(s) (e.g. nipple reconstruction or tattooing, surgery to other breast to match size and shape)	<input type="checkbox"/>	<input type="checkbox"/>
d. Other (please specify)	<input type="checkbox"/>	<input type="checkbox"/>

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## Section 6: Satisfaction with the care you received

**Q25.** These questions ask about the Consultant Surgeon in charge of your breast reconstruction surgery.

**Did you feel that he / she:**

	Definitely disagree	Somewhat disagree	Somewhat agree	Definitely agree
a. Was competent?	1	2	3	4
b. Gave you confidence?	1	2	3	4
c. Involved you in the decision-making process?	1	2	3	4
d. Was reassuring?	1	2	3	4
e. Answered all your questions?	1	2	3	4
f. Made you feel comfortable?	1	2	3	4
g. Was thorough?	1	2	3	4
h. Was easy to talk to?	1	2	3	4
i. Understood what you wanted?	1	2	3	4
j. Was sensitive?	1	2	3	4
k. Made time for your concerns?	1	2	3	4
l. Was available when you had concerns?	1	2	3	4

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**Q26.** These questions ask about members of the medical team other than the Consultant Surgeon in charge of your care. (e.g. nurses and other doctors who looked after you).

**Did you feel that they:**

	Definitely disagree	Somewhat disagree	Somewhat agree	Definitely agree
a. Were professional?	1	2	3	4
b. Treated you with respect?	1	2	3	4
c. Were knowledgeable?	1	2	3	4
d. Were friendly and kind?	1	2	3	4
e. Made you feel comfortable?	1	2	3	4
f. Were thorough?	1	2	3	4
g. Made time for your concerns?	1	2	3	4

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**Q27. Overall, did you feel you were treated with respect and dignity while you were in the hospital?**

- Yes, always
- Yes, sometimes
- No
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**Q28. Overall, how would you rate the care you received?**

- Excellent
- Very good
- Good
- Fair
- Poor
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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