The Royal College of Surgeons of England



# Questionnaire for women who have recently had mastectomy 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 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 did not have a reconstruction, and therefore this questionnaire only relates to your experiences after mastectomy.

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 <u>your recent mastectomy</u> 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
Sec	tion 2: Satisfaction with the information you were given by the people treating you
Q4.	<u>How much</u> information about mastectomy surgery was given to you before your operation?
	Not enough
	The right amount
	Too much

#### Q5. How satisfied or dissatisfied were you with the information you received about:

The state of the s		Comowhat	Comovibat	1/05/
	Very dissatisfied	dissatisfied	Somewhat satisfied	Very satisfied
a. How the mastectomy 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. How much pain to expect during recovery?	1	2	3	4
e. What other women experience with their mastectomy surgery?	1	2	3	4
f. What the scars would look like?	1	2	3	4
Q6. Even though you did not have a breast reconstruction information you were given about reconstruction.  How much information about breast reconstruction.	n <u>before you l</u>	nad your ma	astectomy.	<u>r</u>
information you were given about reconstruction	n <u>before you l</u>	nad your ma	astectomy.	<u>r</u>
information you were given about reconstruction.  How much information about breast reconstruction mastectomy?  Not enough  The right amount	on <u>before you h</u> uction was giv	nad your ma	estectomy.	<u>in any</u>
information you were given about reconstruction  How much information about breast reconstruction  mastectomy?  Not enough The right amount Too much  Q7. Did you receive information about the benefit	on <u>before you h</u> uction was giv	nad your ma	estectomy.  Defore you	<u>in any</u>
information you were given about reconstruction  How much information about breast reconstruction  mastectomy?  Not enough The right amount Too much  Q7. Did you receive information about the benefit of the following ways?	on <u>before you h</u> uction was giv	nad your ma	estectomy.  Defore you	<u>in any</u>
information you were given about reconstruction.  How much information about breast reconstruction mastectomy?  Not enough The right amount Too much  Q7. Did you receive information about the benefit of the following ways?  a. Discussion with a surgeon	on <u>before you h</u> uction was giv	nad your ma	estectomy.  Defore you	<u>in any</u>

#### Section 3: Choices about breast reconstruction

Q8. We are interested in why some women do not have breast reconstruction with or 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 <u>immediate breast reconstruction</u> from now on.

We understand that there may be lots of reasons why you did not have an <u>immediate</u> breast reconstruction.

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

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

	this question. Otherwise, please move onto question 10.		
	Why did you choose not to have immediate breast reconstruction?		
		Agree	Disagree
a.	My cancer treatment was my sole priority		
b.	I was not concerned with how my breast area would look after mastectomy		
C.	I did not feel as though I knew enough about the immediate breast reconstruction		
d.	I did not have enough time to decide about having an immediate breast reconstruction		
e.	I was worried about the length of time needed to recover after an immediate breast reconstruction		
f.	I was worried about the complications that could happen after an immediate breast reconstruction		
	Somewhat dissatisfied  Somewhat satisfied  Very satisfied		
Q <sup>*</sup>	I1. Do you hope to have a breast reconstruction operation at some poir  Yes  No  If No please ignore question 12 and move onto question 13.	nt in the	future?
Q'	12. If you answered Yes to question 11, has the option of a future breas been discussed with the doctors and nurses who are treating you?  Yes  No	t recons	truction

Q9. If you chose not to accept the offer of immediate breast reconstruction please answer

#### **Section 4: Managing your pain**

Q13. How would you desc mastectomy operation	ribe the pain you experienced <u>in the first 24 hours</u> after your on?
No pain at all	
Mild pain	
Moderate pain	
Severe pain	
Q14. How would you desc mastectomy operation	ribe the pain you experienced <u>in the first week</u> after your on?
No pain at all	
Mild pain	
Moderate pain	
Severe pain	
Q15. Do you think the hos	spital staff did everything they could to help control your pain?
Yes, definitely	
Yes, to some extent	
No	

#### **Section 5: Your experiences after surgery**

Q16. 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 b. A wound in your breast or armpit that opened up and required you to have more surgery c. A wound infection that required you to have antibiotics d. Some of the breast skin that remained after your mastectomy turned dark and died e. Pain or tenderness in your chest, arm or armpit that has still not gone away f. Numbness in your chest, arm or armpit that has still not gone away g. Fluid (seroma) collecting in your breast or armpit area that required removal with a needle or drain h. Swelling (lymphoedema) of the arm on the side that you had your surgery i. Difficulty moving your shoulder and arm on the side that you had your surgery j. A blood clot in your legs (deep venous thrombosis) that required your blood to be thinned (anticoagulation) with injections or tablets k. A blood clot in your lungs (pulmonary embolus) I. A heart attack (acute myocardial infarction) m. Other (please specify below) Q17. Did you receive psychological support or counselling from a healthcare professional after your surgery? Yes No

Three month patient questionnaire
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Q18. Did you see a physiotherapist after yo	our surgery?	
Yes		
No		
Q19. Did you use a <u>lymphoedema service</u> a	after your surg	gery?
Yes		
No		
Q20. Since you were discharged, have you further treatment or surgery related to Yes		
Q21. Have you had the following treatmen	nts since your	mastectomy?
a. Radiotherapy	Tes	
b. Chemotherapy		
c. Hormone drug therapy (e.g. tamoxifen)		
d. Specialist palliative care		
e. Breast reconstruction surgery		
f. Other (please specify below)		
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#### Section 6: Satisfaction with the care you received

### Q22. These questions ask about the <u>Consultant Surgeon</u> in charge of your <u>mastectomy surgery</u>. Did you feel that he / she:

	<b>,</b>	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
١.	Was available when you had concerns?	1	2	3	4

## Q23. These questions ask about <u>members of the medical team</u> 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

	Overall, did you feel yo hospital?	ou were treated with respect and dignity while you were in the
,	Yes, always	
,	Yes, sometimes	
	No	
O25	Overall, how would you	
	Excellent	u rate the care you received?
	-	u rate the care you received?
	Excellent	u rate the care you received?
	Excellent Very good	u rate the care you received?

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.

