

COMICE Well-Being Study

Section 1 Presurgical assessment

Q1 What investigations did you have before surgery?

| | | |
|------------------------|-----|----|
| Ultrasound | Yes | No |
| Fine needle aspiration | Yes | No |
| X-ray mammography | Yes | No |
| MRI | Yes | No |

If not answered spontaneously prompt

Q2 How thoroughly was your cancer investigated before surgery?

Q2a

Record response and ask if she felt she was investigated:

Too thoroughly About right Too few investigations

Explore further and ask if she thought she had the right number of tests before surgery.

Q2b

Were the number of tests about right, too many or too few?

About right Too few Too many

Q3 Were any of the tests distressing (refer to list in Q1)

| | | |
|------------------------|-----|----|
| Ultrasound | Yes | No |
| Fine needle aspiration | Yes | No |
| X-ray mammography | Yes | No |
| MRI | Yes | No |

If any of the tests were found to be distressing ask how distressing they were?

| | | | | |
|------------------------|-------------------|----------------------|------------------------|------------------|
| Ultrasound | – Not distressing | Slightly distressing | Moderately distressing | Very distressing |
| Fine needle aspiration | – Not distressing | Slightly distressing | Moderately distressing | Very distressing |
| X-ray mammography | – Not distressing | Slightly distressing | Moderately distressing | Very distressing |
| MRI | – Not distressing | Slightly distressing | Moderately distressing | Very distressing |

Q3a

If any of the tests were distressing ask what was distressing and record the answer.

Section 2 Surgery

Q4 What type of surgery did you have?

Unilateral mastectomy
Bilateral mastectomy
Quadrant mastectomy
Wide local excision

If they had a mastectomy ask if they had any reconstruction. If yes ask if it was:

TRAM flap
LD
Implant

Q4a

When was the reconstruction carried out?

Immediately Delayed

Q5 How many nights did you spend in hospital (count the first night following surgery as night one)?

_____ nights

Q6 Did you have any problems in hospital following your surgery? Yes No

Q6a

If yes what problems did you have?

- 1.
- 2.
- 3.
- 4.

Q7 Looking back on your surgery were you given a choice about the type of surgery you had? Yes No

Q7a

Was that helpful? Yes No

Q7b

On reflection do you think you made the right decision? Yes No

Q8 How satisfied are you with the shape of your breasts at present?

Very satisfied Satisfied Dissatisfied Very dissatisfied

If the patient had a second operation repeat Questions 5–8.

Q8a

How distressing did you find the second operation?

Not distressing Slightly distressing Moderately distressing Very distressing

Section 3 Adjuvant therapy

Q9 Have you had any treatment following surgery?

| | | | |
|-----------------|-----|----|--|
| Radiotherapy | Yes | No | |
| Chemotherapy | Yes | No | |
| Hormone therapy | Yes | No | – tamoxifen |
| MAB | Yes | No | – trastuzumab (Herceptin; monoclonal antibodies) |

Q9a

If RT how long after surgery did your treatment start? Record in weeks _____ weeks

Was that: the right time too soon too late

Q9b

If CT how long after surgery did your treatment start? Record in weeks _____ weeks

Was that: the right time too soon too late

Q9c

If HT how long after surgery did your treatment start? Record in weeks _____ weeks

Was that: the right time too soon too late

Q9d

If MAB how long after surgery did your treatment start? Record in weeks _____ weeks

Was that: the right time too soon too late

Q10 Are there any other treatments which you think might have benefited you

Record answers

Section 4 MRI

If patient had a scan (refer to Section 1) ask

Q11 How did you feel about the decision about having a scan?

Pleased Not pleased Indifferent

Q11a

On balance did it reassure you or make you anxious?

Reassured me Made me anxious

Why did it reassure you/make you anxious?

Section 5 Research knowledge

Q12 Before agreeing to take part in this study were you aware of any other breast cancer studies which were taking place?

Yes No

Q12a

If yes can you tell me what the studies were about? (record answer)

Q12b

Did it influence you in any way to take part in the study?

Yes No

Q12c

Where did you hear about these studies?

Newspaper Radio TV Magazine Friend/Relative

Section 6 In retrospect

Q13 What aspect of your treatment was done well? (record what patient says)

Q13a

What aspect of your treatment should have been done better? (record what patient says)

Q13b

If you could change one thing about your treatment what would it be? (record what patient says)

Patient name

Patient ID

Patient centre

Date of interview ___//___//___

Interview recorded Yes No

Section 1 Investigations**Q1**Ultrasound Yes No FNA Yes No X-ray Yes No MRI Yes No **Q2 Thoroughness of investigations**

What the patient said

Q2a

Record whether investigated

Too thoroughly About right Too few **Q2b**

Number of tests pre-surgery

About right Too many Too few **Q3 Tests causing distress**Ultrasound Yes No Not distressing Slightly distressing Moderately Very distressingFNA Yes No Not distressing Slightly distressing Moderately Very distressingX-ray Yes No Not distressing Slightly distressing Moderately Very distressingMRI Yes No Not distressing Slightly distressing Moderately Very distressing

Q3a

What was distressing (record what patient says)

Section 2 Surgery**Q4 Operation performed**

Unilateral mastectomy Yes No TRAM LD Implant

Bilateral mastectomy Yes No TRAM LD Implant

Quadrant mastectomy Yes No

Wide local excision Yes No

Q4a

Reconstruction carried out Immediately Delayed

Q5 Nights in hospital

___ nights (excluding preoperative nights)

Q6 Problems in hospital Yes No

Q6a

Problems encountered

1.

2.

3.

4.

Q7 Choice of surgery Yes No

Q7a

Helpful Yes No

Q7b

Right decision Yes No

Q7c

Reconstruction offered Yes No

Q8 Satisfaction with shape of breast

Very satisfied

Satisfied

Dissatisfied

Very dissatisfied

Q8a

Second operation

Q8b

Nights in hospital _____ nights (excluding preoperative nights)

Q8c

Problems in hospital Yes No

Q8d

Problems encountered

1.

2.

3.

4.

Q8e

Choice of surgery Yes No

Q8f

Helpful Yes No

Q8g

Right decision Yes No

Q8h

Reconstruction offered Yes No

Q8i

Satisfaction with shape of breast

Very satisfied

Satisfied

Dissatisfied

Very dissatisfied

Q8j

Second operation level of distress

Not distressing Slightly distressing Moderately distressing Very distressing **Section 3 Adjuvant therapy****Q9 Treatment following surgery**Radiotherapy Yes No (If yes go to Q10a)Chemotherapy Yes No (If yes go to Q10b)Hormone therapy Yes No (If yes go to Q10c)MAB Yes No (If yes go to Q10d)**Q9a**

Radiotherapy _____ weeks

Right time Too soon Too late **Q9b**

Chemotherapy _____ weeks

Right time Too soon Too late **Q9c**

Hormone therapy _____ weeks

Right time Too soon Too late **Q9d**

MAB _____ weeks

Right time Too soon Too late **Q10 Other treatments that might have benefited (list)**

1.

2.

3.

Section 4 MRI

Q11 Decision about having a scan

Pleased Not pleased Indifferent

Q11a

Reassure or make anxious

Reassured me Made me anxious

Response to Q11a

Section 5 Research knowledge

Q12 Aware of other breast cancer studies: Yes No

Q12a

Knowledge of studies

Q12b

Influence to participate in study Yes No

Q12c

Heard about studies from

Newspaper Radio TV Magazine Friend/Relative

Section 6 In retrospect

Q13 Aspects of treatment which were done well

1.

Q13a

Aspects which could have been done better

1.

Q13b

What would you change?

1.