

Consumers' Awareness, Use and Evaluative
Perceptions of Cancer Guidelines:

Phase One - "All about early breast cancer"

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Introduction

The Centre for Behavioural Research in Cancer Control (CBRCC) was commissioned by the Cancer Foundation of Western Australia (CFWA) to conduct an evaluation of consumer guidelines for early breast cancer, colorectal cancer and prostate cancer under the Consumer Participation Project (CPP).

The purpose of the Foundation's Consumer Participation Project is to strengthen and maintain the involvement of consumers in the provision of cancer services, both in services planning and in supporting best practice. By increasing consumer involvement in cancer control, it is hoped that the quality of services, and the level of satisfaction with these services, will be improved. Consumers were involved in this study in two ways: Participants included consumer representatives from the Cancer Foundation Consumer Participation Project and patients identified by the Cancer Registry as having been diagnosed with breast cancer.

Ethics approval was obtained to access patients through the Cancer Registry. Only patients who had been diagnosed between three to six months were selected and invited to participate. Participants signed consent forms before involvement in the various stages of the study.

Research Objectives

The research objectives for phase one were to:

- i) investigate the awareness and use of consumer guidelines for early breast cancer;
- ii) invite consumers to critique the guidelines and identify aspects that may not be meeting consumer needs.

The results were to inform ideas for modifying the guidelines to make them more available and relevant to consumers' needs.

Methodology

The research methodology involved qualitative research in a three –stage process.

Stage 1 included a short telephone interview with patients identified from the cancer registry, with the primary purposes of (i) assessing consumer awareness and use of the early breast cancer guidelines; and (ii) recruiting participants for the second stage of the research. These interviews were conducted by consumer representatives of the Cancer Foundation Consumer Participation Project. This questionnaire is appended as Appendix I.

Stage 2 included a postal survey of interviewees from Stage 1 who expressed interest in further research. Those who agreed to participate were sent a copy of the guidelines, along with a questionnaire (Appendix II) asking them to read and make specific judgements about the guidelines in terms of its content, readability, suitability

and usefulness. The questionnaire also asked whether participants were interested in taking part in a focus group discussion with other patients.

Stage 3 attempted to use a focus group to explore themes emerging from stages 1 and 2, and to probe specific aspects of the guidelines in detail.

Results

Stage 1 - Telephone Interview

In total, 47 patients responded to the telephone survey of a total of 151 who were sent letters from the Cancer Registry.

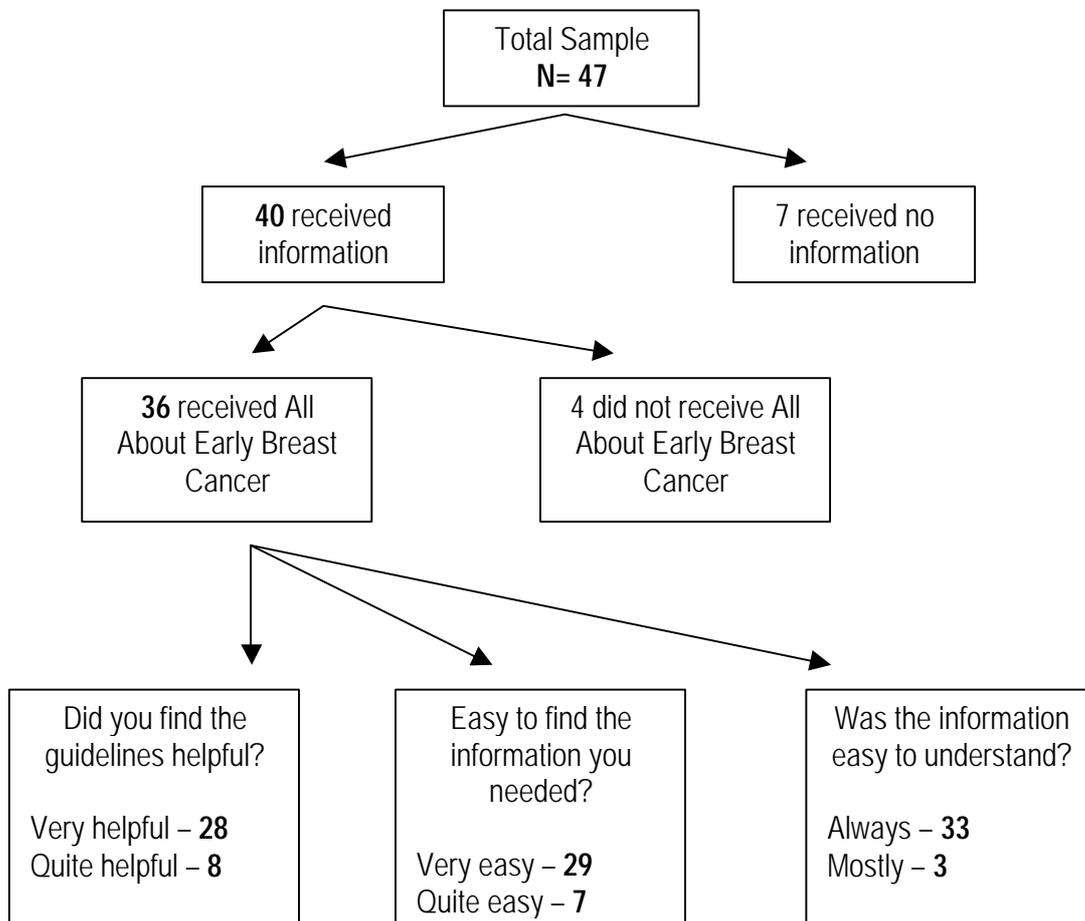
Of the 47 respondents, 40 (85%) had received information on diagnosis, 36 of whom (77% of total) received the guidelines “All about early breast cancer”.

Of the 36 who received “All about early breast cancer” –

- All found the guidelines either very helpful or quite helpful
- All found the information they needed very easily or quite easily
- All found the information always or mostly easy to understand

These results are summarised in Figure 1.

Figure 1. Breast Cancer Telephone Interview Results Summary.



Stage 2 – Postal Survey

43 participants agreed to receive the postal survey and were sent the guidelines and a self-completion questionnaire. However, only 25 (58%) returned a completed questionnaire.

Respondents to the postal survey were asked to read again each chapter of the guidelines and then rate each chapter on 4 point bipolar scales in terms of how helpful, how personally relevant, and how easy/difficult was the language of the chapters. Respondents were further asked to nominate what was ‘most helpful’ in each chapter.

As indicated by Stage 1 results, all of the chapters were rated easy to understand by virtually all respondents. At the end of the questionnaire, in response to an open-ended question, only one respondent indicated that there were words included in the booklet that she did not understand (however she did not indicate which words or in which section). Hence we focus here on the other two ratings where there were differences between respondents and differences between chapters. Complete data are presented in Appendix III. The results for helpfulness and relevance are summarised in Tables 1 and 2.

Overall, the “All about early breast cancer” guidelines were very well received by women who completed the postal survey. There were very few negative comments and most women gave positive feedback and indicated that the guidelines were beneficial. However, Table 1 shows considerable variation between chapters on the extent to which they were considered ‘very’ helpful and ‘very’ relevant.

Helpfulness

There was almost unanimous agreement that all chapters were quite or very helpful: none of the chapters was rated ‘unhelpful’ by more than two respondents and none rated six of the chapters unhelpful. On the other hand, two chapters (1: “What do your tests mean”; and 10: “Common Questions”) were rated ‘very helpful’ by 23 of the 25 respondents (92%) and a further six chapters were rated ‘very helpful’ by 20+ respondents (80%+). On the other hand, the four remaining chapters were considered ‘very helpful’ by 14-15 respondents (56-60%).

Relevance

Only one chapter (10) was considered ‘very relevant’ by at least 20 respondents (80%), and four chapters were considered ‘not relevant’ by 6-10 respondents (24-40%). None of the chapters was considered relevant to all respondents. While relevance was generally related to whether or not the patient required or underwent the treatment referred to in the various chapters (e.g., 2, 4, 5), others are less relevant for idiosyncratic reasons. Most importantly there was no indication that important relevant matters had been omitted.

Table 1. Ratings of helpfulness and relevance

	Very helpful	(Not very helpful)	Relevant	(Not relevant)	Total (helpful + relevant)
Ch. 1	23	(1)	22	(2)	45
Ch. 2	15	(2)	15	(7)	30
Ch. 3	21	(2)	18	(4)	39
Ch. 4	21	-	17	(6)	38
Ch. 5	20	-	13	(10)	33
Ch. 6	20	-	19	(4)	39
Ch. 7	20	-	18	(4)	38
Ch. 8	21	-	17	(3)	38
Ch. 9	14	(2)	13	(6)	27
Ch. 10	23	-	22	(2)	45
Ch. 11	15	(2)	9	(5)	24

Overall, the top two chapters in terms of helpfulness *and* relevance were Chapter 1 “What do your tests mean” and Chapter 10 “Common questions”. Other chapters scoring highly on this combined measure were: Chapter 3 “Deciding between mastectomy and breast conserving treatment”, Chapter 4 “What’s involved in breast conserving treatment”, Chapter 6 “Recommendations about adjuvant treatment”, Chapter 7 “What to expect with adjuvant treatment” and Chapter 8 “Feelings and fears”.

The least helpful and relevant chapters were Chapter 11 “Resources and contacts” (not up to date), Chapter 9 “Costs and practical issues” (also not up to date) and Chapter 2 “Choosing your surgeon” (for those not requiring surgery).

What was most helpful?

Respondents were asked what was most helpful in each chapter. The results are summarised in Table 2.

Table 2. Most helpful information from each chapter.

Chapter	Most helpful	n
Ch. 1	Stages and tumor grade	9
	Lymph node information	5
	All	5
	Oestrogen receptors	3
	Margin notes	3
	Pathology details	1
Ch. 2	Advice on choosing a surgeon	9
	All	6
Ch. 3	Summary/comparison between mastectomy and lumpectomy	10
	All	4
	Reassurance of time to make a decision	2
Ch. 4	Information on side effects of radiation, surgery etc.	11
	All	4
	Description of radiotherapy	3
	Quotes	1
Ch. 5	All	6
	Side effects section	3
	Drawings/illustrations/photographs	3
	Breast reconstruction section	3
Ch. 6	Different treatment/different women	5
	Explanation of chemo and tamoxifen	3
	All	2
	Information on oestrogen	2
	Diagrams	2
Ch.7	Information on side effects	6
	Section on tamoxifen	6
	All	3
	Quotes	3

Ch. 8	Feelings/reactions/coping/others experiences	10
	Reading list/references	5
	All	4
Ch. 9	Accommodation information	6
	Travel information	5
	Contact details of support services	4
	Protheses and wigs	2
	All	2
Ch. 10	Questions to ask your doctor	9
	Lymphoedema section	8
	All	5
Ch. 11	Contacts	7
	Websites	4
	All	4

In response to an open-ended question at the end of the questionnaire, the most frequently nominated *most* useful topic was the section on surgery (Part 2 – 6 respondents). The next most frequent response was ‘the whole book’ (5 respondents). The next most frequent responses were Chapter 1, Chapter 7 and Chapter 6 (3 each).

When asked, very few respondents indicated that they could choose a least useful topic. The most common response was Chapter 11 “Resources and Contacts” (3 respondents).

In terms of information that respondents felt was missing from the booklet, eight indicated that there was something that could be useful for other people with breast cancer. The most common remark (3 respondents) related to the inclusion of post-operative tips relating to physiotherapy and exercise, massage, use of the affected arm etc. Other suggestions included more details on understanding the pathology test, more details about grading and staging, information on pre-surgery procedure (especially in relation to lumpectomy) and more use of other patients’ thoughts and feelings. One woman suggested mentioning “the message that cancer is not a death sentence if caught in time”.

Impact of Reading The Guidelines

Respondents were asked to rate how they felt about their cancer after they first read the guidelines with respect to three aspects: whether they felt more or less puzzled; more or less anxious; and more or less in control (or no different).

- 91% of women who completed the postal survey said they felt less puzzled, and 9% said they felt no different;
- 67% said they felt less anxious, 25% said they felt no different, and 8% said they felt more anxious;
- 75% of women said they felt more in control and 20% said they felt neither more nor less in control.

These questions were important to measure to identify any unintended negative impact of the guidelines. Perhaps understandably, the lowest impact was on lessening anxiety. Nevertheless, two-thirds did experience a lessening of anxiety. All women indicated that they would recommend the guidelines to other people affected by breast cancer.

Overwhelmingly, the general comments on the guidelines were positive in their nature, with comments such as “the booklet was clear and concise”, “whole booklet helpful and well written”, “very thorough and written in plain language for all to understand”.

The main theme from the small number of negative comments related to the timing of receiving the booklet. Several women indicated that they received the booklet too late, and that it would be better received as soon as they had been diagnosed. Women indicated that it would be beneficial to be provided as early as possible so it can be used as a tool to make decisions about treatment options and choices. This research was not designed to identify why some women did not receive the guidelines at the time of diagnosis. The qualitative research suggested that there are individual differences between individual doctors and between medical centres: some provided a comprehensive folder of information, while others provided substantially less.

Stage 3 – Focus Group

It was originally intended that the focus group would provide specific and detailed feedback on the contents and writing style of the *All about early breast cancer* guidelines. It was also anticipated that some part of the group time would be devoted to the women telling their individual stories (including access to and reaction to information). However, in spite of frequent attempts by the moderator to re-direct attention to the booklet, the group members focussed on other aspects of their experiences. This phenomenon probably reflected the findings from the postal survey that the booklet was almost universally considered ‘easy to read’, and that the vast majority found all or most of the chapters ‘helpful’, and, in most cases, ‘relevant’. Hence there was little extra to offer on the guidelines in the group discussion. In fact, all four participants were very positive about the booklet, the language, the pictures, and the information in general. They all felt that the booklet:

- helped them make the right decision about their type of treatment – or reinforced their doctor’s recommendations,
- helped them understand what was involved – although their doctor also played a major role here, and

- helped deal with their feelings – although there was also the belief that coping with such news was something one had to do independently of any written information.

Nevertheless, several relevant points did emerge that are worthy of consideration:

- Even where women did not receive the booklet until after treatment decisions, the information served to reassure them that they had made the right decisions. Hence it is important to make the booklet available even after treatment to those who did not receive it beforehand.
- There was some support for distributing the guidelines during screening. However, this could prove costly. It is likely to be more cost-effective to ensure that all doctors have systems in place that ensure the guidelines are given to all diagnosed patients.
- The booklet would be enhanced by an up-to-date local supplement on all available treatment venues. Three of the four women during the course of the discussion realised that there were *several* treatment centres, but they had been made aware of only one.
- The booklet would be enhanced by an up-to-date local supplement on available local resources.
- With respect to radiation therapy, it was suggested that the word ‘burning’ be used to inform them about potential side effects. References to ‘blistering’ and ‘dry skin’ did not adequately prepare them for what they termed ‘burning’ of the skin.
- One expressed the view that information on the effects of surgery in general could be included.
- Another expressed the view that information on genetics and hereditary factors could be included.

Overall though, very little additional information was gleaned from the focus group. However, it may well be that the group process will be more useful for other guidelines booklets.

Appendix I – Breast Cancer Telephone Interview

NAME: _____ Best Time to Call: _____

TELEPHONE NUMBER: _____ Number of Calls: _____

Breast Cancer Telephone Interview

(Ask for relevant person in the household)

Hello, my name is _____ and I am a volunteer with the Consumer Participation project at the Cancer Foundation of WA. I am ringing in regards to the letter you received recently from the Cancer Registry. They have informed us that you have consented to participate in our telephone survey.

Are you still happy to participate in the survey or would you like some more time to think about it?

Is this a good time to answer the questions or would you like me to call back at some other time that suits you?

If respondent is ready to proceed then assure participant that they can stop at any time:

You can stop the interview at any time without a reason. I will immediately stop and give you time to decide if you would like to carry on. If you decide not to finish that is fine.

If respondent is ready to proceed then ask question one.

1. At the time your breast cancer was diagnosed, or any appointments afterwards as a result of your diagnosis, did your doctor or specialist give you any written information to read? (Please circle yes or no).

Yes ? go to Qu 2.

No ? go to Qu 6.

(Before proceeding to question six, take a few moments to explain the consumer guidelines (see below). There is no need to explain the guidelines at this point if the respondent answers yes to question 1.)

In Australia, we have published a booklet of consumer guidelines titled "All about early breast cancer", for people recently diagnosed with breast cancer. These guidelines explain and discuss many of the issues regarding cancer diagnosis, treatment and outcomes. They are designed to provide the consumer with up-to-date information about their cancer, in order to promote understanding and involvement in the management of their cancer. (If still answer "No" GO TO QUESTION 6).

2. If yes, what did you get to read from the doctor. (Please list interviewees responses).

3. Can you remember which doctor gave you this information? (Please circle one).

- a) GP
- b) Surgeon
- c) Oncologist
- d) Radiotherapist
- e) Other specify _____
- f) Cannot remember

4. Did the doctor give you the information freely, or did you have to ask for it? (please circle one)

- a) he/she gave it to me freely
- b) I had to ask for it

5. Did you receive the specific booklet of consumer guidelines for breast cancer titled, "All about early breast cancer"? (Describe the title, length and cover of the booklet and read explanatory paragraph (as above) if necessary)

Yes ? go to Qu 8.

No ? go to Qu 6.

6. Were you are aware of the breast cancer guidelines before this interview? (Please circle one).

Yes ? go to Qu 7.

No ? go to Qu 12.

7. Do you know where you could get a copy of the guidelines? (Circle responses offered by the interviewee – do not prompt).

- a) GP
- b) Cancer Foundation
- c) Cancer Support Group
- d) Other doctor (oncologist, radiotherapist, surgeon)
- e) Hospital
- f) Cancer Foundation Helpline
- g) No, I was not sure where I could obtain a copy

go to question 12

8. Did you read the guidelines booklet? (If “yes” read a), b) and c) and circle one. If “no”, circle d). **Read out options to prompt their response.**)

- a) yes, entirely ? **proceed to question 9**
- b) yes, most of it ? **proceed to question 9**
- c) yes, some of it ? **proceed to question 8a**
- d) no, not at all ? **proceed to question 8a**

8a. Ask: “Why was that”?

9. Did you find the guidelines helpful? (If “yes” read a), b) and c) and circle one. If “no”, circle d). **Read out options to prompt their response.**)

- a) Very helpful ? **proceed to question 10**
- b) Quite helpful ? **proceed to question 10**
- c) A little bit helpful ? **proceed to question 9a**
- d) Not at all helpful ? **proceed to question 9a**

9a. Ask: “Why was that”?

10. Could you find the information you needed easily in the guidelines? (If “yes” read a) and b) and circle one. If “no” read c) and d), circle one then proceed to question 10a. **Read out options to prompt their response.**)

- a) Very easy ? **proceed to question 11**
- b) Quite easy ? **proceed to question 11**
- c) Quite difficult ? **proceed to question 10a**
- d) Very difficult ? **proceed to question 10a**

10a. Ask: “Why was that”?

11. Was the information written in a way that was easy to understand?
(Read out options and circle one).

- a) always
- b) mostly
- c) sometimes
- d) not at all

12. What is your occupation? _____

13. What was your highest level of education? (please circle one)

- | | |
|------------------------------|---|
| Some primary school | 1 |
| Finished primary school | 2 |
| Some secondary school | 3 |
| TEE/TAE/Year 12 | 4 |
| Some technical or commercial | 5 |
| Technical school/TAFE | 6 |
| Some university | 7 |
| University degree | 8 |
| Refused | 9 |

14. We will soon be carrying out a postal survey, asking people like yourself to read the guidelines and suggest ways in which they can be changed or improved. Would you be willing to participate in this process?

Yes No (please circle one)

(If Yes, ask the consumer for their postal address by saying):

So that we can send you a copy of the guidelines and the postal survey may I please have your postal address?

Name: _____

Address: _____

Appendix II – Breast Cancer Postal Survey

"All About Early Breast Cancer"

Thank you for taking part in our earlier telephone interview on the booklet "All about early breast cancer". In case you no longer have your copy of the booklet, here is another copy. We now wish to ask your opinions on the various Chapters in the booklet.

Before you begin, please read through the "Consumer Participation Project Postal Survey Consent Form".

Instructions

The following chapters are covered in the booklet. Please circle the most relevant statement as it applies to you. There are some questions where you need to write in an answer. For these questions a space is provided for you.

If you make a mistake or wish to change your answer, cross out the mistake and circle the chosen response.

Please read through each Chapter and complete the following questions about each chapter:

Ps. You don't have to do this all in one go!

Part 1 Starting Treatment

Chapter 1 What do your tests mean?

a) How helpful was it? (please tick)

Very helpful	Slightly helpful	Not very helpful	Not at all helpful
? ₁	? ₂	? ₃	? ₄

b) Was it relevant to you? (please tick)

Very relevant	Slightly relevant	Not very relevant	Not at all relevant
? ₁	? ₂	? ₃	? ₄

c) How did you find the language? (please tick)

Easy to understand	Ok to understand	Difficult to understand
? ₁	? ₂	? ₃

d) Please comment on what was most helpful in this chapter

e) Was there anything confusing or puzzling?

Q2

Chapter 2 Choosing your surgeon

a) How helpful was it? (please tick)

Very helpful	Slightly helpful	Not very helpful	Not at all helpful
? ₁	? ₂	? ₃	? ₄

b) Was it relevant to you? (please tick)

Very relevant	Slightly relevant	Not very relevant	Not at all relevant
? ₁	? ₂	? ₃	? ₄

c) How did you find the language? (please tick)

Easy to understand	Ok to understand	Difficult to understand
? ₁	? ₂	? ₃

d) Please comment on what was most helpful in this chapter

e) Was there anything confusing or puzzling?

Part 2 Surgery

Chapter 3 Deciding between mastectomy and breast conserving treatment

a) How helpful was it? (please tick)

Very helpful	Slightly helpful	Not very helpful	Not at all helpful
? ₁	? ₂	? ₃	? ₄

b) Was it relevant to you? (please tick)

Very relevant	Slightly relevant	Not very relevant	Not at all relevant
? ₁	? ₂	? ₃	? ₄

c) How did you find the language? (please tick)

Easy to understand	Ok to understand	Difficult to understand
? ₁	? ₂	? ₃

d) Please comment on what was most helpful in this chapter

e) Was there anything confusing or puzzling?

Q4

Chapter 4 What's involved in breast conserving treatment?

a) How helpful was it? (please tick)

Very helpful	Slightly helpful	Not very helpful	Not at all helpful
? ₁	? ₂	? ₃	? ₄

b) Was it relevant to you? (please tick)

Very relevant	Slightly relevant	Not very relevant	Not at all relevant
? ₁	? ₂	? ₃	? ₄

c) How did you find the language? (please tick)

Easy to understand	Ok to understand	Difficult to understand
? ₁	? ₂	? ₃

d) Please comment on what was most helpful in this chapter

e) Was there anything confusing or puzzling?

Q5

Chapter 5 What's involved in mastectomy?

a) How helpful was it? (please tick)

Very helpful	Slightly helpful	Not very helpful	Not at all helpful
? ₁	? ₂	? ₃	? ₄

b) Was it relevant to you? (please tick)

Very relevant	Slightly relevant	Not very relevant	Not at all relevant
? ₁	? ₂	? ₃	? ₄

c) How did you find the language? (please tick)

Easy to understand	Ok to understand	Difficult to understand
? ₁	? ₂	? ₃

d) Please comment on what was most helpful in this chapter

e) Was there anything confusing or puzzling?

Part 3 Additional treatment

Chapter 6 Recommendations about adjuvant treatment

a) How helpful was it? (please tick)

Very helpful	Slightly helpful	Not very helpful	Not at all helpful
? ₁	? ₂	? ₃	? ₄

b) Was it relevant to you? (please tick)

Very relevant	Slightly relevant	Not very relevant	Not at all relevant
? ₁	? ₂	? ₃	? ₄

c) How did you find the language? (please tick)

Easy to understand	Ok to understand	Difficult to understand
? ₁	? ₂	? ₃

d) Please comment on what was most helpful in this chapter

e) Was there anything confusing or puzzling?

Q7

Chapter 7 What to expect with different adjuvant treatments

a) How helpful was it? (please tick)

Very helpful	Slightly helpful	Not very helpful	Not at all helpful
? ₁	? ₂	? ₃	? ₄

b) Was it relevant to you? (please tick)

Very relevant	Slightly relevant	Not very relevant	Not at all relevant
? ₁	? ₂	? ₃	? ₄

c) How did you find the language? (please tick)

Easy to understand	Ok to understand	Difficult to understand
? ₁	? ₂	? ₃

d) Please comment on what was most helpful in this chapter

e) Was there anything confusing or puzzling?

Part 4 Support and information

Chapter 8 Feelings and fears

a) How helpful was it? (please tick)

Very helpful	Slightly helpful	Not very helpful	Not at all helpful
? ₁	? ₂	? ₃	? ₄

b) Was it relevant to you? (please tick)

Very relevant	Slightly relevant	Not very relevant	Not at all relevant
? ₁	? ₂	? ₃	? ₄

c) How did you find the language? (please tick)

Easy to understand	Ok to understand	Difficult to understand
? ₁	? ₂	? ₃

d) Please comment on what was most helpful in this chapter

e) Was there anything confusing or puzzling?

Q9

Chapter 9 Costs and practical issues

a) How helpful was it? (please tick)

Very helpful	Slightly helpful	Not very helpful	Not at all helpful
? ₁	? ₂	? ₃	? ₄

b) Was it relevant to you? (please tick)

Very relevant	Slightly relevant	Not very relevant	Not at all relevant
? ₁	? ₂	? ₃	? ₄

c) How did you find the language? (please tick)

Easy to understand	Ok to understand	Difficult to understand
? ₁	? ₂	? ₃

d) Please comment on what was most helpful in this chapter

e) Was there anything confusing or puzzling?

Q10

Chapter 10 Common questions

a) How helpful was it? (please tick)

Very helpful	Slightly helpful	Not very helpful	Not at all helpful
? ₁	? ₂	? ₃	? ₄

b) Was it relevant to you? (please tick)

Very relevant	Slightly relevant	Not very relevant	Not at all relevant
? ₁	? ₂	? ₃	? ₄

c) How did you find the language? (please tick)

Easy to understand	Ok to understand	Difficult to understand
? ₁	? ₂	? ₃

d) Please comment on what was most helpful in this chapter

e) Was there anything confusing or puzzling?

Q11

Chapter 11 Resources and contacts

a) How helpful was it? (please tick)

Very helpful	Slightly helpful	Not very helpful	Not at all helpful
? ₁	? ₂	? ₃	? ₄

b) Was it relevant to you? (please tick)

Very relevant	Slightly relevant	Not very relevant	Not at all relevant
? ₁	? ₂	? ₃	? ₄

c) How did you find the language? (please tick)

Easy to understand	Ok to understand	Difficult to understand
? ₁	? ₂	? ₃

d) Please comment on what was most helpful in this chapter

e) Was there anything confusing or puzzling?

Q12

a) Were there any words in the guidelines that you did not understand? (please tick)

Yes	No
? ₁	? ₂

b) If yes, which words were difficult to understand?

Q13

What, if anything, was missing from the guidelines that you think could be useful for other people with breast cancer?

Q14

When you first read the guidelines when your cancer was diagnosed, how did it make you feel? (Please tick in the appropriate box)

a) After I first read the guidelines about my cancer I felt:

More puzzled	Less puzzled	No difference
? ₁	? ₂	? ₃

b) After I first read the guidelines about my cancer I felt:

More anxious	Less anxious	No difference
? ₁	? ₂	? ₃

c) After I first read the guidelines about my cancer I felt:

Less in control	More in control	No difference
? ₁	? ₂	? ₃

Q15

In your opinion, what was the most useful topic or piece of information, if any, in the consumer guidelines for breast cancer?

Q16

In your opinion, what was the least useful topic or piece of information, if any, in the consumer guidelines for breast cancer?

Q17

a) Would you recommend these guidelines to other people with breast cancer?
(Please tick)

Yes	No
? ₁	? ₂

b) If no, why not?

Q18

Do you have any other general comments about the guidelines?

You have finished the survey!

Please sign and date the “Consumer Participation Project Postal Survey Consent Form”. Don’t forget to indicate if you would like further information on participating in a focus group.

Please mail the consent form and this survey in the reply paid envelope.

Thank you very much for your help.

Appendix III – Helpfulness, Relevance and Language Data

Table A 1. Helpfulness

	<i>Very helpful</i>	<i>Slightly helpful</i>	<i>Not very helpful</i>	<i>Not at all helpful</i>
Ch. 1	23	1		1
Ch. 2	15	4		2
Ch. 3	21		1	1
Ch. 4	21	1		
Ch. 5	20	2		
Ch. 6	20	3		
Ch. 7	20	3		
Ch. 8	21	3		
Ch.9	14	6	1	1
Ch. 10	23			
Ch. 11	15	7	1	1

Table A 2. Relevance

	<i>Very relevant</i>	<i>Slightly relevant</i>	<i>Not very relevant</i>	<i>Not at all relevant</i>
Ch. 1	22	1		2
Ch. 2	15	3	2	5
Ch. 3	18	1		4
Ch. 4	17	1		6
Ch. 5	13	1	2	8
Ch. 6	19	1		4
Ch. 7	18	2		4
Ch. 8	17	4	3	
Ch.9	13	5	3	3
Ch. 10	22		1	1
Ch. 11	9	8	5	

Table A 3. Language

	<i>Easy to understand</i>	<i>OK to understand</i>
Ch. 1	23	2
Ch. 2	22	
Ch. 3	24	
Ch. 4	23	
Ch. 5	23	
Ch. 6	22	1
Ch. 7	23	
Ch. 8	24	
Ch.9	23	
Ch. 10	24	
Ch. 11	23	1