

Consumers' Awareness, Use and Evaluative Perceptions of Cancer  
Guidelines:  
Phase Three – "Localised prostate cancer: A guide for men and their  
families"

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CBRCC Report 030826

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

Phase Three - "Localised Prostate Cancer: A guide for  
men and their families"

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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 prostate 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 prostate 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 localised prostate 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. However, insufficient numbers indicated an interest in further participation.

## Results

### *Stage 1 – Telephone Interview*

In total, 37 patients responded to the telephone survey of a total of 130 who were sent letters from the Cancer Registry.

Of the 37 respondents, 27 (73%) had received information on diagnosis, 15 of whom (40% of total) received the guidelines “Localised prostate cancer: A guide for men and their families”.

These results were more favourable than those of the Colorectal Cancer Guidelines – “Guidelines for the prevention, early detection and management of colorectal cancer: A guide for patients, their families and friends” – where only 14% of respondents had received the guidelines prior to their interview (4 out of 28 respondents).

In contrast, the results from the telephone interviews for the Breast Cancer Guidelines - “All about early breast cancer” - showed that 77% of respondents had received the guidelines prior to their interview (36 out of 47 respondents).

Of the 15 who received “Localised prostate cancer: A guide for men and their families” –

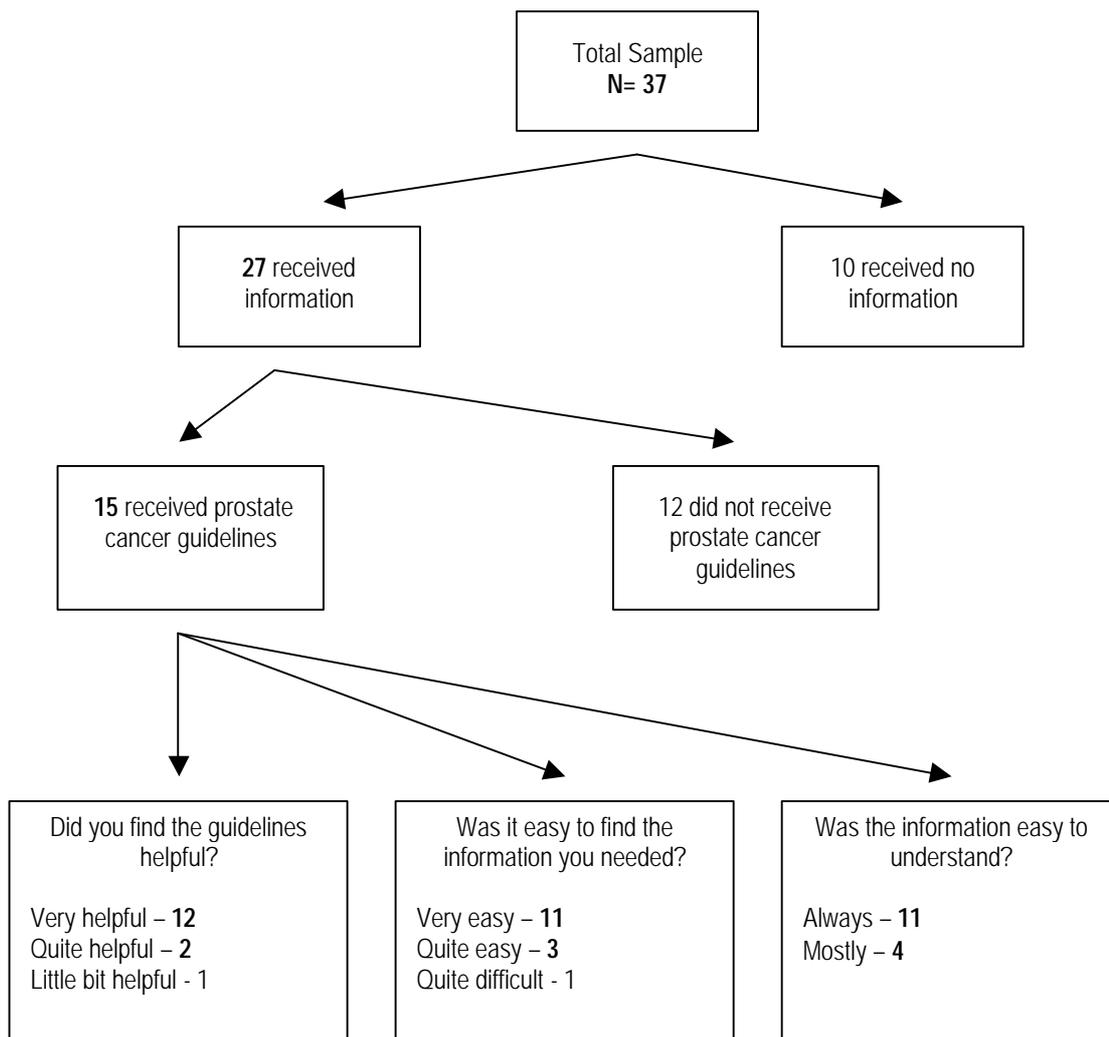
- 14 found the guidelines either very helpful or quite helpful
- 14 found the information they needed very easily or quite easily
- All found the information always or mostly easy to understand

These results are summarised in Figure 1.

The Colorectal Cancer Guidelines interviews showed that one patient received the Guidelines, but did not read them. Apart from this, the results from the Colorectal Cancer Guidelines were similar in that, those who had read the Guidelines all found them either very helpful or quite helpful, all found the information they needed very easily, and all found the information always or mostly easy to understand.

The results for the Breast Cancer Guidelines again were similar: All found the guidelines either helpful or quite helpful; all found the information they needed very easily or quite easily; and all found the information always or mostly easy to understand.

**Figure 1. Prostate Cancer Telephone Interview Results Summary**



**Stage 2 - Postal Survey**

35 participants agreed to receive the postal survey and were sent a copy of the Guidelines and a self-completion questionnaire. However, only 12 (34%) 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 3 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.

11 out of the 13 chapters were rated by all respondents as either “easy” or “ok” to understand. Two chapters (Appendix 1 and Appendix 2) were rated as “difficult to understand” by one respondent. However, at the end of the questionnaire, in response to an open-ended question, none of the respondents indicated that there were any words included in the booklet that he did not understand.

These results are dissimilar to the findings from both the Breast Cancer and Colorectal Cancer Guidelines postal survey, where all of the chapters were rated as easy to understand by virtually all respondents. The breast cancer guidelines and the colorectal cancer guidelines were both very well received by those who completed the postal survey. There were few negative comments and most respondents gave positive feedback and indicated that the guidelines were beneficial.

### ***Helpfulness***

Four respondents rated Appendix 5 and References as not very helpful. Two respondents rated Appendix 1 and one respondent rated Summary, Chapter 2, Appendix 2 and Appendix 3 as 'not at all, or not very helpful'.

Three chapters (Chapter 1, Chapter 3 and Chapter 4) were rated as very helpful by 11 of the 12 respondents (92%). One chapter (Chapter 2) was rated as very helpful by 10 respondents and a further three chapters (Summary, Appendix 2, and Glossary) were rated as very helpful by 9 respondents. Chapter 5 and Appendix 1 were rated by 8 and 6 respondents respectively as 'very helpful'. The references section, along with Appendix 3, 4 and 5, were only rated as helpful by 4 or less respondents.

Complete data are presented in Appendix III. The results for helpfulness and relevance are summarised in Table 1.

These results are in contrast to the results for helpfulness of the Breast Cancer Guidelines and Colorectal cancer Guidelines, where there was almost unanimous agreement that all chapters were quite or very helpful.

### ***Relevance***

Four chapters (Chapter 1, Chapter 3, Chapter 4, and Appendix 2) were considered to be very relevant for 10 out of the 12 respondents (83%). A further three chapters (Summary, Chapter 2 and Glossary) were considered to be very relevant by 9 respondents. None of the chapters was considered relevant by all respondents.

**Table 1. Ratings of helpfulness and relevance.**

	Very helpful	(Not very helpful)	Very Relevant	(Not very relevant)	Total (helpful + relevant)
<b>Summary</b>	9	(1)	9	(1)	18
<b>Ch. 1</b>	11		10		21
<b>Ch. 2</b>	10	(1)	9		19
<b>Ch. 3</b>	11		10		21
<b>Ch. 4</b>	11		10		21
<b>Ch. 5</b>	8		8		16
<b>References</b>	1	(4)	1	(4)	2
<b>Appendix 1</b>	6	(2)	7	(2)	13
<b>Appendix 2</b>	9	(1)	10		19
<b>Appendix 3</b>	3	(1)	2	(4)	5
<b>Appendix 4</b>	3		3		6
<b>Appendix 5</b>	4	(4)	5	(4)	9
<b>Glossary</b>	9		9		18

Overall, the top chapters in terms of helpfulness *and* relevance were Chapters 1, 3 and 4. The least helpful and relevant chapters were “References”, Appendix 3 and Appendix 4.

***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
<b>Summary</b>	All helpful	4
	Simple, plain, clear language	2
<b>Chapter 1</b>	Diagrams	4
	Explanation of what is cancer/prostate cancer	4

<b>Chapter 2</b>	Levels, stages, gradings, scorings	7
	All helpful	2
<b>Chapter 3</b>	All helpful/informative	5
<b>Chapter 4</b>	Life after treatment (eg. Psycho-social, erection problems, incontinence)	5
	What if my cancer comes back?	3
	All helpful	2
<b>Chapter 5</b>	All helpful	5
	Information on radiotherapy	3
<b>References</b>	All helpful	2
<b>Appendix 1</b>	All helpful	2
	TNM System	2
<b>Appendix 2</b>	All helpful	6
<b>Appendix 3</b>	General information on clinical trials (eg, what is involved)	4
<b>Appendix 4</b>	All helpful (for those who might need it)	5
	Websites	2
<b>Appendix 5</b>	All helpful	3
<b>Glossary</b>	All helpful	6

In response to an open-ended question at the end of the questionnaire, the most frequently nominated response was that Chapter 3 “What are the treatments and how do I decide”, was *most* useful, as it “lets one know where one stands”, and provides

“an excellent general coverage”. Other responses included Chapter 1 (especially page 12 “what is prostate cancer?”) and the explanation of the Gleason score.

When asked, four respondents indicated that they could choose a least useful topic. Their responses included: the resource list (Appendix 4); the References section; the Questions section (Chapter 5); and the tables and statistics (“they are just not accurate”).

One respondent made a general comment that there was “too much repetition” and that he “believed that the message could be imparted in half the size of the booklet”. Another commented that “as a young family man diagnosed with prostate cancer, more information should be given on how it affects your family and your future”.

In terms of information that respondents felt was missing that could be helpful for other people with prostate cancer, four respondents indicated items. All of the respondents had different suggestions that they would have liked more information on. These included expanding the information on T3 patients, more information on reoccurrence, positive case studies (especially in relation to possibility of pain and lack of sexual function), hormone therapy and Orchiectomy as a treatment.

#### *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). These questions are important to identify any unintended negative impact of the guidelines.

- 58% said they felt less puzzled and 42% said they felt no different
- 50% said they felt less anxious, 8% said they felt more anxious and 34% said they felt no different (8% didn't give any answer)
- 50% said they felt more in control and 42% said they felt no different (8% didn't give any answer)

One respondent stated that the guidelines made him feel “more anxious because of the reoccurrence section”.

11 out of the 12 respondents indicated that they would recommend the guidelines to other people affected by prostate cancer. The reason given by the one respondents for not recommending the guidelines was that he thought it could be “made better”, although he did say “it is better than nothing and does have some good information – so with conditions I would recommend it”.

Generally speaking, the comments on the guidelines were positive in their nature, with comments such as “very informative and clearly written”, “better stage by stage information source, excellent reference book” and “eminently readable, and has a reassuring quality”.

Matters mentioned as puzzling or confusing in specific chapters were as follows:

- Summary – “It misses the facts. Stress the fact that biopsies are not painful, and confirm diagnosis”.

- Chapter 1 – “Would like to see more emphasis on individual uncertainty, therefore stressing the need for biopsy”.
- Chapter 2 – “Measuring systems and how they inter-relate is confusing (mentioned 4 times)”.
- Chapter 3 – “Don’t like the use of tables because everyone is different”, “Insufficient information on hormone therapy”.
- Chapter 4 – “No information on further treatments if cancer returns after hormone therapy/radiotherapy treatment”, “Information does not really cover my stage: PSA 16 – T3 – Gleason 8”.
- Chapter 5 – “The last 2 paragraphs seem to refer to surgery rather than radiotherapy”, “What is localised prostate cancer (p.61) reference to the seminal vesicles being ‘excluded’ and in the ‘what would you take out?’ (p.64) being ‘included’”, “Emphasise biopsy”.
- References – “Should incorporate websites”.
- Appendix 1 – “Too many ‘systems’ (TNM, Jewett), I think it is too much information”, “Systems such as TNM & Jewett can make a patient complacent”.
- Appendix 2 – “No information on grade 4 – 6”, “More explanation needed here”.

## Appendix I – Prostate Cancer Telephone Interview

NAME: \_\_\_\_\_ Best Time to Call: \_\_\_\_\_

TELEPHONE NUMBER: \_\_\_\_\_ Number of Calls: \_\_\_\_\_

### *Prostate 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 prostate 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 "Localised prostate cancer: a guide for men and their families", for people recently diagnosed with prostate 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?**

*(Please list interviewees responses)*

\_\_\_\_\_  
\_\_\_\_\_

**3. Can you remember who 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 prostate cancer titled, “Localised prostate cancer: a guide for men and their families”?**

(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 prostate 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"?**

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**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"?**

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**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"?**

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**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?** (please circle one)

**Yes**  
**No**

(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:** \_\_\_\_\_

Thankyou for your time and cooperation. If you have any questions at any later date you can call the Consumer Participation Project Officer, Chris Massey at the Cancer Foundation of WA.

(Give individual telephone number 9212 4386 only if they ask).

Goodbye

## Appendix II – Prostate Cancer Postal Survey

# 'Localised prostate cancer: a guide for men and their families'

Thank you for taking part in our earlier telephone interview on the booklet "Localised prostate cancer: a guide for men and their families". In case you don't have the booklet, we have enclosed a 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 book consists of a Summary of Contents, 5 Chapters, References, 5 Appendices and a Glossary. Please read through each part of the book and then do the set of questions about each chapter.

For each question, please tick 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 tick the chosen response.

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

**Please read "Summary of contents" and answer Question S.**

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**Question S: "Summary of contents"**

a) How helpful was it? (please tick)

Very helpful	Slightly helpful	Not very helpful	Not at all helpful
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>	? <sub>4</sub>

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

Very relevant	Slightly relevant	Not very relevant	Not at all relevant
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>	? <sub>4</sub>

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

Easy to understand	Ok to understand	Difficult to understand
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>

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

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e) Was there anything confusing or puzzling?

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**Now read Chapter 1 - "Introduction to prostate cancer" - before answering Question 1.**

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**Question 1: "Chapter 1 Introduction to prostate cancer"**

a) How helpful was it? (please tick)

Very helpful	Slightly helpful	Not very helpful	Not at all helpful
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>	? <sub>4</sub>

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

Very relevant	Slightly relevant	Not very relevant	Not at all relevant
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>	? <sub>4</sub>

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

Easy to understand	Ok to understand	Difficult to understand
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>

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

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e) Was there anything confusing or puzzling?

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**Now read Chapter 2 - "Finding out about your cancer" - before answering Question 2.**

**PS. Remember you don't have to do all the chapters in one go!**

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**Question 2:** "Chapter 2 Finding out about your cancer"

a) How helpful was it? (please tick)

Very helpful	Slightly helpful	Not very helpful	Not at all helpful
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>	? <sub>4</sub>

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

Very relevant	Slightly relevant	Not very relevant	Not at all relevant
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>	? <sub>4</sub>

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

Easy to understand	Ok to understand	Difficult to understand
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>

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

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e) Was there anything confusing or puzzling?

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**Now Read Chapter 3 - "What are the treatments and how do I decide?" - before answering Question 3.**

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**Question 3:** "Chapter 3 What are the treatments and how do I decide?"

a) How helpful was it? (please tick)

Very helpful	Slightly helpful	Not very helpful	Not at all helpful
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>	? <sub>4</sub>

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

Very relevant	Slightly relevant	Not very relevant	Not at all relevant
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>	? <sub>4</sub>

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

Easy to understand	Ok to understand	Difficult to understand
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>

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

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e) Was there anything confusing or puzzling?

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**Now read Chapter 4 - "After the treatment is over" - before answering Question 4.**

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**Question 4:** "Chapter 4 After the treatment is over"

a) How helpful was it? (please tick)

Very helpful	Slightly helpful	Not very helpful	Not at all helpful
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>	? <sub>4</sub>

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

Very relevant	Slightly relevant	Not very relevant	Not at all relevant
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>	? <sub>4</sub>

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

Easy to understand	Ok to understand	Difficult to understand
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>

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

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e) Was there anything confusing or puzzling?

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Now read Chapter 5 - "What questions could I ask?" - before answering Question 5.

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**Question 5:** "Chapter 5 What questions could I ask?"

a) How helpful was it? (please tick)

Very helpful	Slightly helpful	Not very helpful	Not at all helpful
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>	? <sub>4</sub>

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

Very relevant	Slightly relevant	Not very relevant	Not at all relevant
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>	? <sub>4</sub>

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

Easy to understand	Ok to understand	Difficult to understand
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>

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

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e) Was there anything confusing or puzzling?

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**You are doing well. Keep it up!**

**Now read "References" before answering Question R.**

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**Question R: "References"**

a) How helpful was it? (please tick)

Very helpful	Slightly helpful	Not very helpful	Not at all helpful
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>	? <sub>4</sub>

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

Very relevant	Slightly relevant	Not very relevant	Not at all relevant
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>	? <sub>4</sub>

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

Easy to understand	Ok to understand	Difficult to understand
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>

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

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e) Was there anything confusing or puzzling?

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**Now read "Appendix 1 Common staging systems" before answering Question A1.**

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**Question A1: "Appendix 1 Common staging systems"**

a) How helpful was it? (please tick)

Very helpful	Slightly helpful	Not very helpful	Not at all helpful
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>	? <sub>4</sub>

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

Very relevant	Slightly relevant	Not very relevant	Not at all relevant
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>	? <sub>4</sub>

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

Easy to understand	Ok to understand	Difficult to understand
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>

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

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e) Was there anything confusing or puzzling?

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Now read "Appendix 2 The Gleason grading system" before answering Question A2.

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**Question A2: “Appendix 2 The Gleason grading system”**

a) How helpful was it? (please tick)

Very helpful	Slightly helpful	Not very helpful	Not at all helpful
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>	? <sub>4</sub>

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

Very relevant	Slightly relevant	Not very relevant	Not at all relevant
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>	? <sub>4</sub>

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

Easy to understand	Ok to understand	Difficult to understand
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>

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

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e) Was there anything confusing or puzzling?

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**Now read “Appendix 3 Clinical trials” before answering Question A3.**

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**Question A3: "Appendix 3 Clinical Trials"**

a) How helpful was it? (please tick)

Very helpful	Slightly helpful	Not very helpful	Not at all helpful
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>	? <sub>4</sub>

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

Very relevant	Slightly relevant	Not very relevant	Not at all relevant
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>	? <sub>4</sub>

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

Easy to understand	Ok to understand	Difficult to understand
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>

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

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e) Was there anything confusing or puzzling?

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**You are into the last few Chapters now!**

**Now read "Appendix 4 Resource list" before answering Question A4.**

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**Question A4: "Appendix 4 Resource list"**

a) How helpful was it? (please tick)

Very helpful	Slightly helpful	Not very helpful	Not at all helpful
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>	? <sub>4</sub>

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

Very relevant	Slightly relevant	Not very relevant	Not at all relevant
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>	? <sub>4</sub>

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

Easy to understand	Ok to understand	Difficult to understand
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>

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

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e) Was there anything confusing or puzzling?

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Now read "Appendix 5 A record of your prostate cancer" before answering Question A5.

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**Question A5: "Appendix 5 A record of your prostate cancer"**

a) How helpful was it? (please tick)

Very helpful	Slightly helpful	Not very helpful	Not at all helpful
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>	? <sub>4</sub>

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

Very relevant	Slightly relevant	Not very relevant	Not at all relevant
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>	? <sub>4</sub>

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

Easy to understand	Ok to understand	Difficult to understand
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>

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

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e) Was there anything confusing or puzzling?

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**Nearly there!**

**Now read "Glossary: What does that word mean?" before answering Question G.**

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**Question G: "Glossary: What does that word mean?"**

a) How helpful was it? (please tick)

Very helpful	Slightly helpful	Not very helpful	Not at all helpful
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>	? <sub>4</sub>

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

Very relevant	Slightly relevant	Not very relevant	Not at all relevant
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>	? <sub>4</sub>

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

Easy to understand	Ok to understand	Difficult to understand
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>

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

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e) Was there anything confusing or puzzling?

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**That's the book finished. Congratulations!**

**Now just a few quick questions and the survey is over.**

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**Question 6**

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

Yes	No
? <sub>1</sub>	? <sub>2</sub>

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

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**Question 7**

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

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**Question 8: ONLY FOR THOSE WHO READ THE GUIDELINES PREVIOUSLY**

**OTHERS GO TO QUESTION 9**

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

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

More puzzled	Less puzzled	No difference
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>

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

More anxious	Less anxious	No difference
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>

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

Less in control	More in control	No difference
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>

**NOW GO TO QUESTION 10**

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**Question 9: ONLY FOR THOSE WHO HAD NOT READ THE GUIDELINES BEFORE THIS SURVEY**

When you read the guidelines, how did it make you feel?  
(Please tick the appropriate box)

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

More puzzled	Less puzzled	No difference
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>

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

More anxious	Less anxious	No difference
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>

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

Less in control	More in control	No difference
? <sub>1</sub>	? <sub>2</sub>	? <sub>3</sub>

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**Question 10**

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

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**Question 11**

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

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**Question 12**

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

Yes	No
<b>?<sub>1</sub></b>	<b>?<sub>2</sub></b>

b) If no, why not?

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**Question 13**

Do you have any other general comments about the guidelines?

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**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 1. Helpfulness

	Very helpful	Slightly helpful	Not very helpful	Not at all helpful
<b>Summary</b>	9	2		1
<b>Ch. 1</b>	11	1		
<b>Ch. 2</b>	10	1	1	
<b>Ch. 3</b>	11	1		
<b>Ch. 4</b>	11	1		
<b>Ch. 5</b>	8	4		
<b>References</b>	1	7	4	
<b>Appendix 1</b>	6	4	2	
<b>Appendix 2</b>	9	2	1	
<b>Appendix 3</b>	3	8	1	
<b>Appendix 4</b>	3	8		
<b>Appendix 5</b>	4	4	4	
<b>Glossary</b>	9	3		

Table 2. Relevance

	Very relevant	Slightly relevant	Not very relevant	Not at all relevant
<b>Summary</b>	9	2		1
<b>Ch. 1</b>	10	2		
<b>Ch. 2</b>	9	3		
<b>Ch. 3</b>	10	2		
<b>Ch. 4</b>	10	2		
<b>Ch. 5</b>	8	4		
<b>References</b>	1	7	4	
<b>Appendix 1</b>	7	3	2	
<b>Appendix 2</b>	10	2		
<b>Appendix 3</b>	2	6	4	
<b>Appendix 4</b>	3	8		
<b>Appendix 5</b>	5	3	4	
<b>Glossary</b>	9	3		

Table 3. Language

	Easy to understand	Ok to understand	Difficult to understand
<b>Summary</b>	11	1	
<b>Ch. 1</b>	12		
<b>Ch. 2</b>	10	2	
<b>Ch. 3</b>	12		
<b>Ch. 4</b>	12		
<b>Ch. 5</b>	12		
<b>References</b>	7	5	
<b>Appendix 1</b>	8	3	1
<b>Appendix 2</b>	9	2	1
<b>Appendix 3</b>	8	4	
<b>Appendix 4</b>	8	3	
<b>Appendix 5</b>	9	3	
<b>Glossary</b>	11	1	