

Consumers' Awareness, Use and Evaluative Perceptions of Cancer
Guidelines:
Phase Two – "Guidelines for the prevention, early detection and
management of colorectal cancer"

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

Phase Two - "Guidelines for the prevention, early
detection and management of colorectal cancer: A guide
for patients, their families and friends"

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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 colorectal 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 two were to:

- i) investigate the awareness and use of Consumer Guidelines for colorectal 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 colorectal 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, 28 patients responded to the telephone survey of a total of 150 who were sent letters from the Cancer Registry.

Of the 28 respondents, 16 (57%) had received information on diagnosis, only 4 of whom (14% of total) received the book “Guidelines for the prevention, early detection and management of colorectal cancer: A guide for patients, their families and friends”.

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

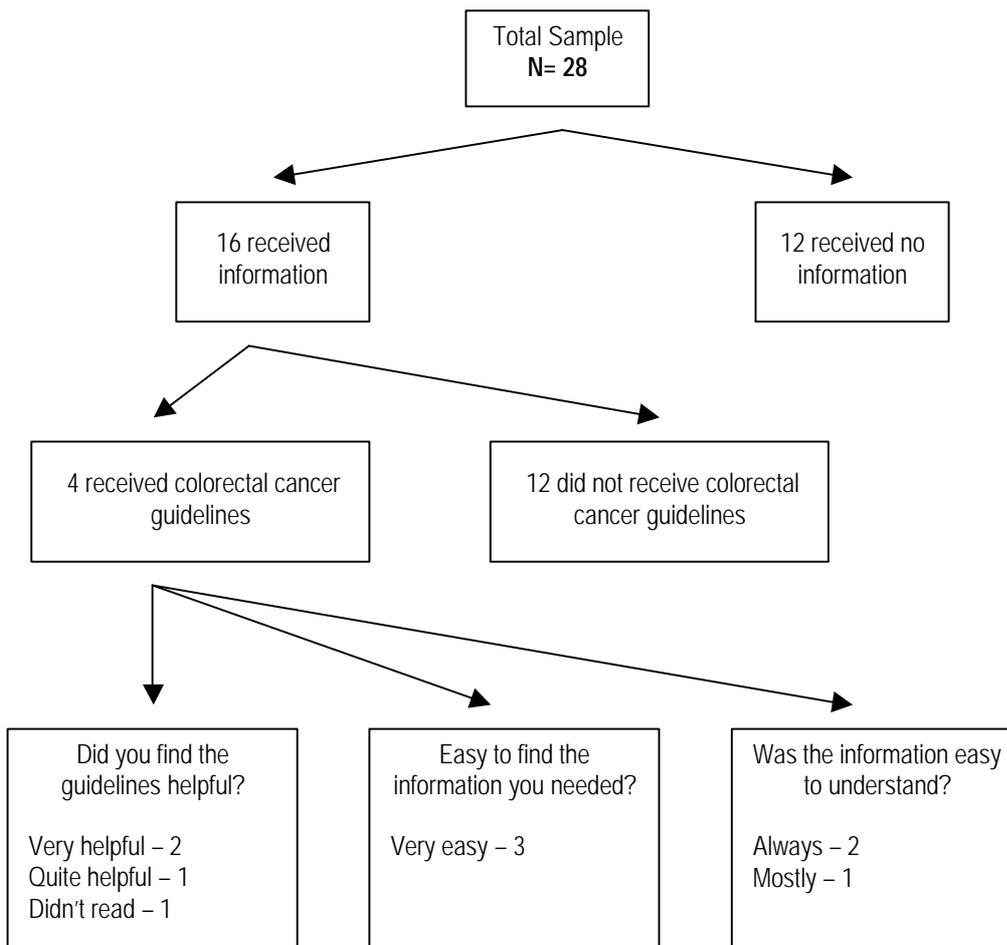
Of the 4 who received “Guidelines for the prevention, early detection and management of colorectal cancer: A guide for patients, their families and friends” –

- 1 patient didn't read the guidelines
- All who had read the guidelines found the guidelines either very helpful or quite helpful
- All who had read the guidelines found the information they needed very easily and
- All who had read the guidelines found the information always or mostly easy to understand

These results are summarised in Figure 1.

Again, in contrast, the results from the Breast Cancer Guidelines interviews showed that of the 36 who received the Guidelines, 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. Colorectal Cancer Telephone Interview Results Summary.



Stage 2 - Postal Survey

26 participants agreed to receive the postal survey and were sent the Guidelines and a self-completion questionnaire. However, only 12 (46%) returned a completed questionnaire. A number of respondents did not complete all items in the 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.

All of the chapters were rated as either "easy" or "ok" to understand by 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 he/she did not understand. The difficult words were indicated as being "quite a few" in Chapter 12, on bowel cancer in families. The respondent stated that most of chapter 12 was confusing, and that "this is the most difficult of the chapters and I find it hard to remember much of it".

These results are similar to the findings from the Breast Cancer Guidelines postal survey, where all of the chapters were rated as easy to understand by virtually all respondents. The

“All about early breast cancer” guidelines were also very well received by those who completed the postal survey. There were few negative comments and most women gave positive feedback and indicated that the guidelines were beneficial.

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

Overall, the “Guidelines for the prevention, early detection and management of colorectal cancer: A guide for patients, their families and friends” was very well received by those who completed the postal survey. There were very few negative comments and most respondents gave positive feedback and indicated that the guidelines were beneficial.

Any negative comments generally related to small suggestions made in relation to very specific aspects of each chapter. These will be presented under *Impact of reading the guidelines*.

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 twelve of the chapters unhelpful. One chapter (“Introduction”) was rated ‘very helpful’ by all of the respondents, and a further seven chapters were rated ‘very helpful’ by 10+ respondents (83%+). The remaining six chapters were considered ‘very helpful’ by 8-9 respondents (67-75%)

Relevance

Only one chapter (3) was considered ‘very relevant’ by at least 11 respondents (92%), six chapters were considered ‘very relevant’ by 10 respondents (83%) and three chapters were considered ‘not relevant’ by 1-2 respondents (8-17%). None of the chapters was considered relevant to all respondents.

Table 1. Ratings of helpfulness and relevance.

	Very helpful	(Not very helpful)	Relevant	(Not relevant)	Total (helpful + relevant)
Introduction	12	0	10	1	22
Ch. 1	11	0	10	0	21
Ch. 2	11	0	10	1	21
Ch. 3	10	1	11	1	21
Ch. 4	10	1	10	1	20
Ch. 5	11	0	10	0	21
Ch. 6	9	1	7	2	16
Ch. 7	9	0	8	0	17
Ch. 8	9	0	7	2	16
Ch. 9	10	0	9	1	19
Ch. 10	8	1	7	1	15
Ch. 11	10	1	10	1	20
Ch. 12	8	1	7	0	15
Word meanings	9	0	9	1	18

Overall, the top chapters in terms of helpfulness *and* relevance were “Introduction”, Chapters 1 – 6 and Chapter 11 (all “20” or more).

The least helpful and relevant chapters were Chapter 10 “Reducing your risk of bowel cancer” and Chapter 12 “Bowel cancer in families”.

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
Introduction	Pictures and diagrams	5
	Clear explanations	3
	All helpful	2
Ch. 1	Stages of bowel cancer	5
	All helpful	4
Ch. 2	Symptoms	3

	Effects eg. emotional, physical	2
	All helpful	2
Ch. 3	Treatment options	4
	All helpful	2
Ch. 4	Explanation of procedures	5
	All helpful	1
Ch. 5	All helpful	3
	Ask surgeon questions	2
Ch.6	All helpful	3
	Options to be considered	2
Ch. 7	All helpful	2
	Regular check ups	2
	What I can do to help myself	2
Ch. 8	What to expect	3
	All helpful	2
Ch. 9	Comprehensive set of questions	5
	All helpful	3
Ch. 10	Healthy diet	5
Ch. 11	Screening	4
	Warning signs	2
Ch. 12	Awareness for family members	4
	Genetics	3
	All helpful	1
Word meanings	All helpful	5

In response to an open-ended question at the end of the questionnaire, the most frequently nominated response was that the whole book was *most* useful, and that there was no emphasis on rating one section more useful than another.

When asked, very few respondents indicated that they could choose a least useful topic. The most common response was Chapter 12 “Bowel cancer in families” (2 respondents).

In terms of information that respondents felt was missing from the booklet, five indicated that there was something missing that could be useful for other people with colorectal cancer. All of the respondents had different suggestions, including the suggestion for more information on how to recognise the signs and how to overcome embarrassment, and to insist that the doctor refers on. One respondent suggested the inclusion of religion as being most helpful.

One respondent indicated that ‘receiving the booklet on being told you have cancer’ would be beneficial.

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.

- 67% said they felt less puzzled and 8% said they felt no different (25% didn’t give any answer)
- 58% said they felt less anxious, 8% said they felt more anxious and 17% said they felt no different (17% didn’t give any answer)
- 50% said they felt more in control, 8% said they felt less in control and 25% said they felt no different (17% didn’t give any answer)

One respondent stated that “I was very sorry I didn’t have the guidelines when the bowel cancer was first detected as that was the time I felt anxious, puzzled and less in control”. Another respondent stated that the booklet made her feel more anxious and less in control, “but not in a bad way”.

75% of respondents indicated that they would recommend the guidelines to other people affected by bowel cancer.

Generally speaking, the comments on the guidelines were positive in their nature, with comments such as “easy to understand explanations”, “made me feel more prepared – able to answer family and friends worries”, “easy to comprehend”, “clear and forthright”.

The main themes of any negative comments were very specific and related to various chapters as follows:

- Chapter 1 – “Need more information relating to the occurrence of benign tumors.”
- Chapter 2 – “Need information on gaining referrals to a specialist”; “A section on costs that could be expected may be helpful.”
- Chapter 4 – “May be a bit too long for some readers, suggest making the information a little more succinct.”
- Chapter 5 – “Would like examples of how the colon looks after a resection”; “Need some information on length and severity of side effects related to clinical trials.”
- Chapter 6 – “What about secondaries in the lymph nodes?”; “What will the blood tests indicate?”

- Chapter 7 – “There is no mention of effects of chemotherapy (This information can be obtained from the oncologist)”; “Would like information on check-ups in the first 3-4 years of remission, especially in relation to colonoscopy or sigmoidoscopy.”
- Chapter 8 – “Would like to see further development of this material”; “I suggest that doctors need to be educated on how to react to symptoms.”
- Chapter 9 – “Would like some information on length and severity of side effects.”
- Chapter 10 – “Would like to see sizes of portions and an example of diet.”
- Chapter 11 – “Why was colonoscopy not mentioned as part of this chapter?”; “I suggest education for doctors.”
- Chapter 12 – “It was hard to comprehend a lot of this chapter.”

Stage 3 – Focus Group

The intention of the focus group was to provide specific and detailed feedback on the contents and writing style of the *Guidelines for the prevention, early detection and management of colorectal cancer: A guide for patients, their families and friends*.

In general, they all felt that the booklet was:

- well written
- easy to read
- clear language – no jargon that can’t be understood

One respondent stated that it provided a good reference for family (especially children), and in fact may be more beneficial for the family in the first instances, when the patient may not be able to take in all the information at once. In addition, all respondents “wished they had the booklet earlier”, for access to information from specific chapters when it was needed.

Having access to the chapters when they are needed was something that was stated as being more significant than reading the book as a whole, when it may become too overwhelming and an overload of information to read all in one go. In addition, all focus group participants said that they would have liked to have received the guidelines earlier than what they did.

Focus group participants identified that the first questions being asked by patients diagnosed with bowel cancer were: “What are we going to do?” and “How are we going to get rid of it?” It may be beneficial too rethink the order in which the chapters are organised, as the participants believed that they could be presented in a different order to address these questions first. For example, one participant mentioned that Chapter 5: “What are the treatment options?” should be presented earlier in the book, as this was one of the first issues that arose after diagnosis of bowel cancer. In particular, she mentioned the pictures on page 31 as being important information that may be more beneficial to the patient if presented in an earlier section of the book.

Similar to the results from the breast cancer guidelines focus group, participants expressed the view that information on the effects of surgery in general could be included; for example, information on pain relief, side effects and basic surgery processes. Also, it was suggested that updated sheets may need to be included with information provided on any new treatment options, for example new treatment using radioactive implants for secondaries in the liver.

Focus group participants mentioned that they would like access to some information on questions arising in dealing with families, friends and other people with cancer. Specifically: “How do I tell my family I have cancer?” and “How do I deal with people who have cancer?” were questions that participants felt were concerns that they needed some guidance in dealing with.

An interesting observation from one focus group participant was that he believed there might be a “divide between the Cancer Foundation and medical people” involved in treating cancer. He stated that he thought the “medical people were reluctant to hand out materials from the Cancer Foundation”. The same participant also stated that the Cancer Foundation local offices “are very helpful, knowledgeable, qualified, experienced people” and that he had “confidence in the people he spoke to”.

In relation to Internet resources, it was recognised that while some websites can be beneficial, others can be a trap for patients looking for reliable information. As the Internet becomes a more frequently used tool for searching for and sourcing information, the Cancer Foundation may look at producing a guide to reliable web sites on the Internet about various types of cancer.

Overall then, apart from re-ordering the chapters to deal earlier with questions like ‘what to do about the cancer’, all of the group members were positive about the current format and content.

Appendix I – Colorectal Cancer Telephone Interview

NAME: _____ Best Time to Call: _____

TELEPHONE NUMBER: _____ Number of Calls: _____

Colorectal 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 colorectal 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 "Guidelines for the prevention, early detection and management of colorectal cancer: A guide for patients, their families and friends", for people recently diagnosed with bowel 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 colorectal cancer titled, "Guidelines for the prevention, early detection and management of colorectal cancer: A guide for patients, their families and friends"? (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 colorectal 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 – Colorectal Cancer Postal Survey

'Guidelines for the prevention, early detection and management of colorectal cancer: A guide for patients, their families and friends'

Thank you for taking part in our earlier telephone interview on the booklet "Guidelines for the prevention, early detection and management of colorectal cancer: A guide for patients, their families and friends". 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 an "Introduction", 12 Chapters and a "Word Meanings" section. 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! 😊

Try to do 3 chapters a day. Many Thanks!

Please read the Introduction and answer Question 1.

Question I: "Introduction"

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?

Now read Chapter 1 - "How does bowel cancer start?" - before answering Question 1.

Question 1: "Chapter 1 How does bowel cancer start?"

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?

Now read Chapter 2 - "How might bowel cancer affect me?" - before answering Question 2.

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

Question 2: "Chapter 2 How might bowel cancer affect me?"

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?

Now Read Chapter 3 - "Dealing with bowel cancer and its treatments" - before answering Question 3.

Question 3: "Chapter 3 Dealing with bowel cancer and its 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?

Now read Chapter 4 - "What procedures might I have?" - before answering Question 4.

Question 4: "Chapter 4 What procedures might I have?"

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?

Now read Chapter 5 - "What are the treatment options?" - before answering Question 5.

Question 5: "Chapter 5 What are the treatment options?"

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?

You are doing well. Keep it up!

Now read Chapter 6 - "What if I have secondaries in my liver?" - before answering Question 6.

Question 6: "Chapter 6 What if I have secondaries in my liver?"

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?

Now read Chapter 7 - "After the treatment is over" - before answering Question 7.

Question 7: "Chapter 7 After the treatment is over"

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?

Now read Chapter 8 - "What if the bowel cancer comes back?" - before answering Question 8.

Question 8: “Chapter 8 What if the bowel cancer comes back?”

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?

You are into the last few Chapters now!

Now read Chapter 9 - “What questions could I ask if I have bowel cancer” - before answering Question 9.

Question 9: "Chapter 9 What questions could I ask if I have bowel cancer?"

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?

Now read Chapter 10 - "Reducing your risk of bowel cancer" - before answering Question 10.

Question 10: "Chapter 10 Reducing your risk of bowel cancer"

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?

Now read Chapter 11 - "Early detection" - before answering Question 11.

Question 11: "Chapter 11 Early detection"

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?

Now read Chapter 12 - "Bowel cancer in families" - before answering Question 12.

Question 12: "Chapter 12 Bowel cancer in families"

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?

Nearly there!

Now read "What does that word mean" on page 73 - 81 before answering Question W.

Question W: "What does that word 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?

That's the book finished. Congratulations!

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

Question 15

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?

Question 16

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

**Question 17: ONLY FOR THOSE WHO READ THE GUIDELINES PREVIOUSLY
OTHERS GO TO QUESTION 18**

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
? 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

NOW GO TO QUESTION 19

Question 18: 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
? ₁	? ₂	? ₃

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

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

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

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

Question 19

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

Question 20

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

Question 21

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

Yes	No
? ₁	? ₂

b) If no, why not?

Question 22

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 A1. Helpfulness

	Very helpful	Slightly helpful	Not very helpful	Not at all helpful
Introduction	12			
Ch. 1	11	1		
Ch. 2	11	1		
Ch. 3	10	1	1	
Ch. 4	10		1	
Ch. 5	11			
Ch. 6	9			1
Ch. 7	9	1		
Ch. 8	9	2		
Ch.9	10	1		
Ch. 10	8	2	1	
Ch. 11	10			1
Ch. 12	8	3	1	
Word meanings	9	2		

Table A 2. Relevance

	Very relevant	Slightly relevant	Not very relevant	Not at all relevant
Introduction	10		1	
Ch. 1	10	2		
Ch. 2	10	1	1	
Ch. 3	11		1	
Ch. 4	10			1
Ch. 5	10			
Ch. 6	7	1		2
Ch. 7	8	2		
Ch. 8	7	2	2	
Ch.9	9	1	1	
Ch. 10	7	3	1	
Ch. 11	10			1
Ch. 12	7	5		
Word meanings	9	1	1	

Table A 3. Language

	Easy to understand	OK to understand
Introduction	10	2
Ch. 1	10	1
Ch. 2	10	2
Ch. 3	11	1
Ch. 4	11	1
Ch. 5	10	
Ch. 6	9	
Ch. 7	8	1
Ch. 8	10	1
Ch.9	11	
Ch. 10	9	2
Ch. 11	10	1
Ch. 12	7	4
Word meanings	8	3