

## PATIENT QUESTIONNAIRE 2: 1 WEEK FOLLOW UP (T2)

### OVERVIEW OF QUESTIONS

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#### 1) General health

How would you describe your general health during the past week?

worst  
imaginable  
health state

0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10

best  
imaginable  
health state

#### 2) Treatment choice and strength of treatment preference

Which treatment do you prefer at this time?

- best supportive care **with** chemotherapy
- best supportive care **without** chemotherapy
- don't know (please skip the next question)

How strong is the above preference?

- |                       |                       |                       |                       |
|-----------------------|-----------------------|-----------------------|-----------------------|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| not<br>strong         | rather<br>strong      | strong                | very<br>strong        |

#### 3) Amount of information

Please indicate what best indicates your view about how much information you have received about cancer treatment over the past few weeks

- |                                  |                           |                                       |                                       |                                     |                         |                                |
|----------------------------------|---------------------------|---------------------------------------|---------------------------------------|-------------------------------------|-------------------------|--------------------------------|
| <input type="radio"/>            | <input type="radio"/>     | <input type="radio"/>                 | <input type="radio"/>                 | <input type="radio"/>               | <input type="radio"/>   | <input type="radio"/>          |
| way too<br>little<br>information | too little<br>information | slightly too<br>little<br>information | the right<br>amount of<br>information | slightly too<br>much<br>information | too much<br>information | way too<br>much<br>information |

Have you received any treatment-related information you would rather not have received?

- Yes
- No

**4) Mental adjustment to cancer scale [51]**

**5) Adapted Lerman's Cancer Worry Scale [50]**

	Not at all	Sometimes	Often	Always
1 Have you thought about cancer in the past week?	1	2	3	4
2 Have these thoughts affected your mood?	1	2	3	4
3 Have these thoughts interfered with your ability to do daily activities?	1	2	3	4

**6) Satisfaction with quality of information**

Please indicate your level of **satisfaction** with the **quality of information**...

	Dissatisfied	Slightly dissatisfied	Neutral	Slightly satisfied	Satisfied	Very much satisfied
1 About treatment-related adverse events	1	2	3	4	5	6
2 About any effects of treatment on the size of the tumour	1	2	3	4	5	6
3 About the effect of treatment on survival	1	2	3	4	5	6

**7) Balanced presentation of information**

There are two treatment options: best supportive care with or without chemotherapy.

Did you feel the information about this treatment choice was presented in a balanced way?

- No, clearly in favour of BSC plus chemotherapy
- No, slightly in favour of BSC plus chemotherapy
- Yes, balanced
- No, slightly in favour of BSC alone
- No, clearly in favour of BSC alone

**8) Other comments about information received**

If you have any other comments about the information you received about cancer treatment over the past few weeks, please write them down below:

.....

.....

.....

**9) Evaluation of information**

How unpleasant did you find the information about the available treatment options?

- |                       |                       |                       |                       |                       |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Not unpleasant        | Slightly unpleasant   | Quite unpleasant      | Unpleasant            | Very unpleasant       |

How shocking did you find the information about the available treatment options?

- |                       |                       |                       |                       |                       |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Not shocking          | Slightly shocking     | Quite shocking        | Shocking              | Very shocking         |

How frightening did you find the information about the available treatment options?

- |                       |                         |                       |                       |                       |
|-----------------------|-------------------------|-----------------------|-----------------------|-----------------------|
| <input type="radio"/> | <input type="radio"/>   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Not frightening       | Slightly<br>frightening | Quite<br>frightening  | Frightening           | Very<br>frightening   |

How threatening did you find the information about **adverse events**?

- |                       |                         |                       |                       |                       |
|-----------------------|-------------------------|-----------------------|-----------------------|-----------------------|
| <input type="radio"/> | <input type="radio"/>   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Not threatening       | Slightly<br>threatening | Quite<br>threatening  | Threatening           | Very<br>threatening   |

How threatening did you find the information about **tumour response** to treatment?

- |                       |                         |                       |                       |                       |
|-----------------------|-------------------------|-----------------------|-----------------------|-----------------------|
| <input type="radio"/> | <input type="radio"/>   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Not threatening       | Slightly<br>threatening | Quite<br>threatening  | Threatening           | Very<br>threatening   |

How threatening did you find the information about **survival**?

- |                       |                         |                       |                       |                       |
|-----------------------|-------------------------|-----------------------|-----------------------|-----------------------|
| <input type="radio"/> | <input type="radio"/>   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Not threatening       | Slightly<br>threatening | Quite<br>threatening  | Threatening           | Very<br>threatening   |

## 10) Information received from oncologist

In your recent meeting with the oncologist, did the oncologist provide any information about adverse events?

- Yes
- No

In your recent meeting with the oncologist, did the oncologist provide any information about tumour response (any changes in the size of the tumour) to treatment?

- Yes
- No

In your recent meeting with the oncologist, did the oncologist provide any information about estimated survival?

- Yes
- No

## 11) Treatment subjective knowledge

The following 3 questions are about how you judge your knowledge about the two treatment options. On a scale of 1-10, where

- |                          |                         |
|--------------------------|-------------------------|
| 1= extremely poor        | 6= sufficient           |
| 2= very poor             | 7= more than sufficient |
| 3= poor                  | 8= good                 |
| 4= strongly insufficient | 9= very good            |
| 5= insufficient          | 10= excellent           |

1. How would you judge your knowledge about the advantages of cancer treatments? .....
2. How would you judge your knowledge about the disadvantages of cancer treatments? .....
3. How would you judge your knowledge about cancer? .....

## 12) Perceived participation

		Doctor alone	Mostly the doctor	Both equally	Mostly me	Me alone
1	Who was involved in deciding if the risks and benefits of treatment were acceptable for you?	1	2	3	4	5
2	Who was involved in choosing between treatment options?	1	2	3	4	5

Do you feel you had a choice between the treatment options?

Yes

No

Do you feel your opinion mattered when choosing between treatment options?

Yes

No

## 13) Hospital Anxiety and Depression Scale (HADS) [48]

### 14) Objective risk

Please provide your best estimate of the risk of experiencing severe diarrhoea as a side effect of chemotherapy

..... %

Please provide your best estimate of the chance that chemotherapy will shrink the tumour by 50%

..... %

### 15) Objective knowledge

- |   |   |       |       |
|---|---|-------|-------|
| 1 | If treated with chemotherapy, no radiotherapy will be necessary   | Right | Wrong |
| 2 | When the tumour is growing, chemotherapy is the only way to ease symptoms                               | Right | Wrong |
| 3 | The main goal of best supportive care is to ease symptoms   | Right | Wrong |
| 4 | Treatment with chemotherapy will prolong survival by 6 months on average                                | Right | Wrong |
| 5 | Patients receiving best supportive care alone experience more pain than patients receiving chemotherapy | Right | Wrong |

### 16) Subjective risk

In my opinion, the risk of experiencing adverse events related to chemotherapy is:

- Very high
- High
- Neither high nor low
- Low
- Very low

In my opinion, when receiving treatment with chemotherapy - compared to best supportive care alone- the risk of the tumour continuing to grow is:

- Much higher
- Higher
- Slightly higher
- Neither higher nor lower
- Slightly lower
- Lower
- Much lower

In my opinion, when receiving treatment with chemotherapy - compared to best supportive care alone- the risk of experiencing pain is:

- Much higher
- Higher
- Slightly higher
- Neither higher nor lower
- Slightly lower
- Lower
- Much lower

**17) Decision Evaluation Scale [54]**

**18) Treatment attitudes: valuations**

How appropriate do you feel treatment with **best supportive care alone** would be for you? ..... (0-10)

How appropriate do you feel treatment with **chemotherapy** would be for you? ..... (0-10)

**19) Health-related quality of life: EORTC QLQ-C15-PAL [49]**